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QUALITY OF LIFE AND SEXUAL HEALTH AMONG TRANSGENDER PEOPLE AND PEOPLE LIVING WITH HIV IN SWEDEN

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QUALITY OF LIFE AND SEXUAL HEALTH AMONG TRANSGENDER PEOPLE AND PEOPLE LIVING WITH HIV IN SWEDEN

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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ABSTRACT

Background: The overarching objective of public health policy in Sweden has a clear focus on equitable health throughout the population and includes a commitment to reduce avoidable health inequalities. Trans (transgender) people constitute a population that is highly affected by social and health inequalities. People living with HIV in the era of effective antiretroviral therapy (ART) with full access to treatment can live long, fulfilling and productive lives, yet social conditions such as stigma and discrimination continue to contribute to negative health outcomes.

Aim: This project studies quality of life (QoL) and sexual health in two populations: trans people and people living with HIV.

Methods: Data for this thesis is derived from two large cross-sectional studies, targeting people living with HIV (Paper I–II) and trans people (Paper III–IV). In 2013–2014, a nationwide representative study was conducted in 17 infectious disease clinics and needle exchange programs across Sweden (Paper I–II) (n=1097). For studies III–IV, data was collected via a web-based survey targeting trans people in Sweden in 2015 (n=796).

Results: In Paper I, we found that QoL among people living with HIV included in the study was high overall. Lower QoL was associated with having comorbidities, internalized stigma, hopelessness and experiencing negative changes to sex life after HIV diagnosis. In Paper II, we examined the direct and indirect associations between sexual satisfaction and contributing factors among people living with HIV. Sexual dissatisfaction was reported among 49% of respondents. Path analyses revealed that, among both women and men, negative changes to sex life after the HIV diagnosis were directly associated with sexual dissatisfaction. In addition, not being involved in an intimate relationship and perceiving the obligation to disclose HIV status to sexual partners as a barrier to finding a long-term partner were indirectly associated with sexual dissatisfaction. In Paper III, it was found that self-rated health, self-reported disability and QoL among trans people included in the study were associated with experiencing negative or incompetent healthcare experiences. In addition, poorer health outcomes were associated with limited access to legal gender recognition and with identifying as non-binary. The results from Paper IV indicated that sexual satisfaction was relatively low among respondents (46%) and was associated with having multiple current sexual partners, satisfaction with partner relationship, absence of negative mood symptoms, possibilities to discuss sexual matters in healthcare context and no history of sex in exchange for money. In addition, results revealed generally low condom use and HIV testing, both motivated by low risk perception, lack of knowledge of trans-friendly clinics and sexual practices that do not require a condom.

Conclusions: Despite good treatment outcomes and generally high QoL, people living with HIV face stigma, poor mental health and various sexual health challenges that have a bearing on people's QoL and sexual satisfaction. Factors related to trans people's health and QoL are

similar to those of the general population in addition to trans-related distal factors such as legal gender recognition and experiences of healthcare incompetence in trans-related issues.

Key words: trans people, people living with HIV, quality of life, sexual satisfaction, stigma, Sweden

LIST OF SCIENTIFIC PAPERS

- I. Zeluf-Andersson G, Eriksson LE, Schönnesson LN, Höijer J, Månehall P, Ekström AM. *Beyond viral suppression: the quality of life of people living with HIV in Sweden*. AIDS Care. 2018. doi 10.1080/09540121.2018.1545990
- II. Schönnesson LN, Zeluf G, Garcia-Huidobro D, Ross MW, Eriksson LE, Ekström AM. *Sexual (dis)satisfaction and its contributors among people living with HIV infection in Sweden*. Arch Sex Behav. 2018; 47(7):2007
- III. Zeluf G, Dhejne C, Orre C, Nilunger Mannheimer L, Deogan C, Höijer J, Ekéus Thorson A. *Health, disability and quality of life among trans people in Sweden—a web-based survey*. BMC Public Health. 2016;16(1):903
- IV. Zeluf-Andersson G, Dhejne C, Deogan C, Nilunger Mannheimer L, Ekéus Thorson A. *Sexual health and sexual satisfaction in a population of self-identified trans people*, In manuscript

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LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
aOR	Adjusted odds ratio
ART	Antiretroviral treatment
CD 4	Cluster of differentiation 4
CI	Confidence interval
HAART	Highly active antiretroviral treatment
HIV	Human immunodeficiency virus
HRQoL	Health-related quality of life
LGB	Lesbian, gay and bisexual
LGBTQ	Lesbian, gay, bisexual, transgender and queer
MSM	Men who have sex with men
OR	Odds ratio
mL	milliliter
PTS	Post-traumatic stress
QoL	Quality of life
RNA	ribonucleic acid
SRHR	Sexual and reproductive health and rights
STI	Sexually transmitted infection
UNAIDS	United Nations Joint Program on HIV/AIDS
VAS	Visual analogue scale
VIF	Variance inflation factor
WHO	World health organization

PREFACE

In 2014, I was a research assistant at the Department of Public Health Sciences at Karolinska Institutet and became involved in the study ‘Living with HIV in Sweden’ (‘Att leva med hiv i Sverige’) – a nation-wide study about the quality of life (QoL) of people living with HIV in Sweden. Anna Mia Ekström, who was the principal investigator for the project, recruited me to help with data collection. Later, in the autumn of 2015, I was involved in a second project, “Health for all” – a study about the health and health determinants of trans people in Sweden. As a research assistant in the project, I was involved from the early stages of study design and my role was to coordinate the project. In the process of developing the questionnaire, we incorporated instruments concerning QoL and sexual health that were similar to those we used in the study ‘Living with HIV in Sweden’. Since I was interested in a PhD position and as I was involved in both projects, I saw an opportunity to study QoL in two very different groups of people, trans people and people living with HIV. Both groups are exposed to prevailing stigma and discrimination in our society.

I am by no means inferring that one can or should compare trans people with people living with HIV. Being trans is related to a person’s identity while HIV is an infection, a diagnosis, and a person living with HIV does not necessarily see their HIV diagnosis as a part of their identity. However, social determinants of health are similar for all people regardless of their gender identities and health status. Moreover, disparities in health and wellbeing are often seen as, besides biological factors, a result of social inequalities. Thus, health outcomes are largely shaped by social, economic, behavioral and structural factors which can often be targeted through policy. This is my point of departure in this project.

These studies were conducted with the financial support of the Public Health Agency of Sweden. The studies included here also constitute the largest self-reported surveys conducted in Sweden to date among people living with HIV and among trans people. I would like to thank each and every respondent in this project: all 1,100 respondents in the study “Living with HIV in Sweden” and the 796 respondents in the study “Health for all”. It is thanks to your willingness to share your experiences that research like this is possible. I hope this thesis can be useful in providing an updated picture of the different aspects of life that are important to be targeted when attempting to improve overall QoL among people living with HIV and trans people.

1 BACKGROUND

1.1 QUALITY OF LIFE

1.1.1 The concept of quality of life

Quality of life (QoL) is a concept that lacks a uniform definition and there is no “gold standard” on how to assess it. Generally, QoL can be described as feelings of happiness, satisfaction, contentment with life and the ability to cope [1,2]. Some researchers have tried to conceptualize QoL. For instance, Calman (1984) proposed the expectation model, which is a measure of the gap between an individual’s aspirations, hopes and goals and the individual’s actual experiences [1]. Hörnqvist (1982) argued that an individual’s QoL is a result of the need satisfaction within six main spheres of life: structural, material, activity, social, physical and psychological [3]. Despite various conceptualizations and operationalizations of QoL, there is a general belief that most people are familiar with the expression ‘quality of life’ and have an intuitive understanding of what it comprises [2]. In addition, there is a consensus among researchers that QoL should be subjectively evaluated and that it is a multidimensional concept, incorporating different life aspects [2].

Unlike QoL, the term *health-related quality of life* (HRQoL) is more specific [2]. HRQoL can be used as a clinical assessment tool in different patient groups as well as for people without a health-related condition. Although HRQoL, similarly to QoL, lacks a single definition, it often incorporates aspects and assessments of general health and physical, emotional and social functioning [2]. Many HRQoL instruments focus on health status, functional status and a variety of symptoms (e.g. pain, fatigue, insomnia, anxiety, etc.). These assessments are appropriate for clinical purposes when comparing different therapies and aiming to reduce toxicity and symptoms [2]. QoL entails more than physical aspects of health, which is why most instruments cover aspect related to emotional and social functioning [2]. For example, it has been shown that patients with cancer, while reporting some decline in satisfaction within various life domains, reported similar general QoL compared to the general population [4]. This and similar findings could be explained by the assumption that QoL is a relative and dynamic concept – it changes and adapts over time, according to different individual aspirations and circumstances [4]. Calman (1984) explains that people who might seem to have major problems, including a serious health condition or disability, are still able to have good QoL. They are able to achieve this either by adjusting their expectations to a new life situation and thus narrowing the gap between their expectations and achievements, and/or by their ability to rise above the problems through personal growth and personal development [1].

There are many different instruments that can be used for QoL assessments. Some are generic and can be used to assess QoL among various populations with or without a health condition or disability [2]. The most commonly used generic instruments combine assessments of

physical, social and emotional functioning (such as the SF-36 and EQ-D5) where respondents choose their response from a set of alternatives [2]. These instruments vary in length and dimension and at what level of detail they assess QoL [2]. Other instruments are disease-specific and are used to assess QoL in different groups, such as patients with cancer. These instruments usually include assessments of a variety of specific symptoms in addition to functional and overall health [2].

As mentioned above, QoL is assessed differently depending on the definition and conceptualization used. While some studies use instruments that are designed to assess HRQoL, others use instruments designed to assess overall or general QoL, and might use a single item for that assessment. In this project, the assumption is that QoL is a subjective, multidimensional and context-specific concept. It means different things for different people and during different periods in life. In addition, it is related to various life domains which are also very contextual.

1.2 SEXUAL HEALTH AND SEXUAL SATISFACTION

According to the World Health Organization's (WHO) definition, sexual health is "...a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled" [5].

Despite this holistic definition, sexual health is often discussed as a unidimensional concept and discussed in terms of sexually transmitted infections (STI). Recently, there has been a positive shift to a rights-based approach to sexual (and reproductive) health and a new, integrated definition of sexual and reproductive health and rights (SRHR) was adopted by the Lancet Guttmacher Commission. This definition emphasizes that ".....a positive approach to sexuality and reproduction should recognize the part played by pleasurable sexual relationships, trust, and communication in the promotion of self-esteem and overall wellbeing" [6]. The same integrated definition of SRHR spells out sexual satisfaction as a sexual right by saying that all individuals have the right to "have safe and pleasurable sexual experiences" [6].

Sexual satisfaction is thus an important aspect of sexual health. It is further associated with overall well-being and QoL [7,8]. The concept *sexual satisfaction* is a subjective and context-specific construct. There are various definitions to sexual satisfaction but the most commonly

used one is proposed by Lawrance and Byers (1995) who defined sexual satisfaction as “an affective response arising from one’s subjective evaluation of the positive and negative dimensions associated with one’s sexual relationship” [9].

As there are various definitions of sexual satisfaction, there are consequently many different assessment instruments. A systematic review of 197 studies concerning sexual satisfaction found that over 40 different instruments were used to assess sexual satisfaction [7]. The assessment of sexual satisfaction varies across studies; in most studies, it is measured in a relational perspective [7]. The most commonly used instruments include assessments of magnitude of a problem with dyadic relationship [10], or the assessment of different dimensions of sexual relationships with a partner [9]. Other scales assess not only relational but also individual and behavioral aspects of sexuality and measure constructs such as sexual sensations, sexual presence and awareness, sexual exchange, emotional connection or closeness and sexual activity [11]. In addition, some instruments are more focused on sexual function and assess aspects such as erectile dysfunction [7]. Other instruments use a global single question assessing self-reported satisfaction [7].

Henderson et al. (2009), conceptualized sexual satisfaction with the help of the socio-ecological theory, explaining that sexual satisfaction is the outcome of the interaction between proximal and distal factors. According to this conceptualization, sexual satisfaction is related to the interaction between the microsystem (individual level factors such as beliefs, values and emotions), the mesosystem (intimate relationships), the exosystem (social support and extended family) and the macrosystem (laws, ideologies and cultural beliefs) [12].

In this study, we adopt the idea that sexual satisfaction is a subjective, multidimensional concept which is context-specific. It is a result of various factors related not solely to dyadic relationship but also to individual and societal factors.

1.3 LIVING WITH HIV

1.3.1 Global HIV epidemiology

According to the latest report by The United Nation’s Programme on HIV/AIDS (UNAIDS), an estimated 36.9 million (31.1–43.9 million) people are living with HIV globally [13]. Among people with a known HIV diagnosis worldwide, 21.7 million (19.1–22.6 million) have access to antiretroviral treatment (ART) [13]. Since the peak of the epidemic in 2005, AIDS-related deaths have declined by nearly half, yet AIDS-related deaths still constitute a substantial global burden, despite very effective ART and 940,000 people (670,000–1.3 million), an unacceptably high number, are estimated to have died of AIDS-related causes in 2017 [13]. Most of these deaths occurred in Sub-Saharan Africa, albeit with great regional

and national differences. The incidence of HIV has been declining globally since 2000 while the number of people living with HIV has been increasing thanks to increasing access to effective ART [14].

1.3.2 HIV epidemiology in Sweden

Sweden is a low-endemic country with an HIV prevalence of about 0.07%. It is estimated that approximately 7,749 people are living with a diagnosed HIV in Sweden [15] (39% women, 61% men) and between 400–500 individuals are newly diagnosed with HIV each year [16]. The majority of people living with HIV in Sweden have contracted HIV through heterosexual intercourse, either on trips abroad or before migrating to Sweden. While sex between men remains the most common transmission mode domestically, migrants constitute the largest proportion of newly diagnosed cases in Sweden since 1990, and accounted for more than 80% of diagnosed cases in 2017 [16]. According to the national quality registry InfCare HIV in December 2018, 50.6% of people living with HIV in Sweden contracted HIV via heterosexual sex, 31.3% via sex among men, 5.1% via injecting drug use, 2.9% via mother to child, 1.4% via blood products and 5.9% from another/an unknown source [15].

1.3.3 The UNAIDS 90-90-90 targets of treatment cascade

The UNAIDS announced new ambitious targets for the global response to HIV in 2014. These targets, called the 90-90-90 targets, call for countries to, by 2020, ensure that 90% of people living with HIV will know their HIV status, 90% of people who are diagnosed with HIV receive sustained ART and that 90% of people living with HIV who receive ART will achieve viral suppression [17]. The 90-90-90 targets emerged thanks to the fact that viral suppression, as a consequence of access to effective ART, has great benefits both for the individual living with HIV through greatly improved healthy survival as well as for the entire population by reducing the risk of secondary transmission to sexual partners and from mother to child by at least 96% [17]. Globally, the progress towards the 90-90-90 targets is slow but is going in the right direction, even though some countries have had greater progress than others. According to UNAIDS reporting from 2018, three out of four people (55–92%) living with HIV knew their HIV status in 2017. Among those who knew their HIV status, 77% (57–89%) were accessing ART, and 82% (60–89%) of people on treatment had suppressed viral loads [17]. The global progress towards the 90-90-90 targets includes challenges related to each element of the treatment cascade, beginning with knowledge about HIV and HIV diagnosis, linkage to care and retention in care and finally viral suppression. All of these aspects are challenged by weak health systems, lack of access to effective treatment and stigma and discrimination, among others [17].

Sweden was the first country in the world to reach the UNAIDS 90-90-90 target [18]: it is estimated that 90% of HIV cases are diagnosed, 97.5% of diagnosed people living with HIV

are linked to care and 95.3% on ART have achieved viral suppression [15] (Figure 1). Despite these encouraging numbers, the HIV epidemic in Sweden is also characterized by a large proportion of people who are diagnosed late (when CD4 count <350 cells/ml or the person has already been diagnosed with an AIDS-defining illness) [19,20]. It is estimated that approximately half of the annual HIV diagnoses are among late presenters, which is more prominent among foreign-born and older age groups [21].

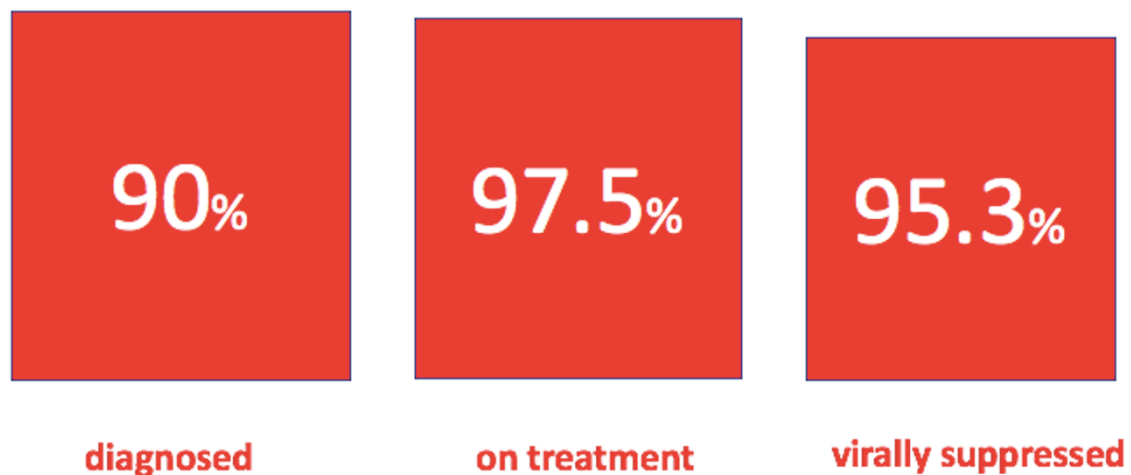


Figure 1. The UNAIDS 90-90-90 targets adjusted for the Swedish treatment cascade in December 2018 (based on data from the national quality registry InfCare HIV [15])

1.3.4 HIV treatment and management—then and now

Since it was first discovered in the early 1980s, the discourse about HIV and AIDS, which for a long time were used synonymously, has changed tremendously. During the 1980s, an HIV diagnosis was equivalent to a death sentence. The early 1980s were also characterized by large misunderstandings and misconceptions about the biology, source and epidemiology of HIV and AIDS [22]. In 1987, the first drug for the treatment of HIV was introduced – azidothymidine (AZT). This drug later proved ineffective as patients quickly developed drug resistance [22]. By 1991, monotherapy of HIV/AIDS had shifted to combination therapy with newer drugs (didanosine [ddi] and zalcitabine or [ddC] for short) in combination with AZT [22]. A breakthrough in the treatment and the prognosis of HIV occurred in 1996, with the introduction of highly active antiretroviral therapy (HAART) – a triple drug treatment, containing protease inhibitors [22,23]. HAART had a quick and significant impact on the health and survival of people living with HIV. The new treatment reduced the risk of opportunistic infections and morbidity through suppression of viral replication and by increasing CD4 cell counts, consequently extending survival [23]. The new treatment was referred to as ‘miraculous’ and the effect it had on patients was so tremendous that it was

seen as an opportunity for a ‘second life’ [23]. Today, antiretroviral treatment (ART) is potent, convenient – usually entails one to two pills a day, and usually well tolerated [24,25].

ART can reduce the concentration of the HIV virus in the blood to undetectable levels within weeks of treatment initiation, which increases CD4 cell counts and survival among people living with HIV [24]. The effect of ART on the reduced risk of transmission of HIV became widely accepted in 2008 when a group of HIV experts released what is now known as the Swiss Consensus Statement [26]. The statement was based on the conclusion that people living with HIV, who achieve viral suppression and have durable undetectable levels of virus in the blood (HIV RNA <40 copies per mL), cannot transmit the virus through sexual contact [27]. Today, there is scientific consensus that the risk of sexual transmission of HIV is nearly non-existing when a person who is living with HIV is durably virally suppressed and has condomless sex with a person who is HIV-negative. This important realization is a result of three large studies conducted among heterosexual couples and couples including men who have sex with men (MSM) between 2007 and 2016 that found no HIV infections among the HIV negative partners in HIV discordant couples where the positive partner was on successful ART (virally suppressed) [28–30]. This incredible effect of ART is something that many people living with HIV worldwide are experiencing and as a result, a new term has emerged – undetectable=untransmittable, or for short – $U=U$.

1.3.5 Living with HIV–biomedical, social and legal realities

Despite significant progress in treatment and prognosis, HIV remains much more associated with stigma and discrimination than most other chronic health conditions [31]. Once on effective treatment and virally suppressed, the management of HIV in Sweden is mostly done by the person living with HIV him/herself, by taking daily an ART dose and many people living with HIV only visit their doctor once or twice a year. The *social* management of HIV, however, takes place ‘outside the clinic’, in the social sphere [31]. In a qualitative study conducted in the United Kingdom in 2016, people living with HIV shared ambivalent experiences of HIV as a condition that is not special as well as experiences of fear, stigma and shame [32]. The history and the historic discourse of HIV, the stigma that is still associated with HIV and its chronic nature, make HIV different from many other conditions [27,32]. Different social aspects of life are affected by an HIV diagnosis. People living with HIV face challenges related to intimate relationships, sexual challenges, disclosure concerns and criminalization of non-disclosure [31,33,34] that differentiate HIV from many other chronic conditions. People living with HIV are also faced with reproductive dilemmas which are multifaceted and include the person’s health status, fear of HIV transmission to child or partner, and restrictive or enabling policies that are in place [35–37]. In Sweden, for example, the majority of in vitro fertilization (IVF) clinics still do not provide IVF services for people

living with HIV, despite the nearly non-existing risk of transmission from mother to child under the conditions of effective treatment [38].

1.3.6 Quality of life among people living with HIV

Today, the life expectancy of people living with HIV with universal access to ART is approaching that of the general population [39]. Research reports suggest that the QoL of people living with HIV on ART is relatively high [40–42], however lower than the QoL of people without HIV, mostly with regard to psychosocial aspects [43,44]. One study, which compared the HRQoL of people living with HIV to that of people with other chronic conditions (diabetes type 1, 2 and rheumatoid arthritis), found that while physical HRQoL was similar between the different groups, mental HRQoL was lower among people living with HIV [45]. Furthermore, a large study from England found that people living with HIV reported lower QoL compared to the general population, even after adjusting for sociodemographic variables and immunological status, antiretroviral therapy and viral load. These reported differences were only prevalent with regard to reported depression and anxiety [43].

Research suggests that various sociodemographic, clinical and psychological factors are associated with the QoL of people living with HIV [46]:

1.3.6.1 Sociodemographic factors

Similarly to the general population, certain sociodemographic factors are also significant with regard to QoL among people living with HIV. It has been suggested that older age is associated with poorer QoL [47–49]. With regard to gender, studies have found gender to be significantly associated with QoL [40,44,47,50]. Unemployment [42,51,52] and financial constraints [40,53] are also reported to be significantly associated with lower QoL. Findings about the associations between partner relationship, children and QoL have been inconsistent (for review see [46]). Studies also suggest that living conditions, including housing conditions, are important to consider with regard to QoL and other health outcomes among people living with HIV. One systematic review from 2016, which investigated the health outcomes and the living situation of people living with HIV in high-income countries, revealed that unstable housing conditions and homelessness are significant barriers to HIV care, access and adherence to ART and sustained viral suppression [54]. Substance use and hazardous consumption of alcohol are other factors found to be associated with lower QoL among people living with HIV [42,46].

1.3.6.2 Clinical factors

Clinical factors associated with lower reported QoL include comorbidities [40,42,48], early calendar diagnosis with HIV [43,53] and symptoms of HIV [42]. As people living with HIV age as a result of effective treatment, other health-related issues become relevant including increasing prevalence of chronic comorbidities [55–58]. Common comorbidities include cardiovascular diseases, kidney disease and various cancers [55–58], among others. Studies from different settings have shown that the prevalence of age-associated comorbidities is significantly higher in people living with HIV [55–57]. These conditions are also thought to have an effect on the overall QoL [58]. The reasons behind these elevated risks, particularly of cardiovascular comorbidities among people living with HIV, are not fully understood but are thought to be partly explained by a complex interaction between the viral infection, ART and other traditional risk factors such as smoking, hypertension, hyperlipidaemia, obesity and others [59,60].

1.3.6.3 Mental health and psychological factors

Viral suppression has become the main indicator of health and treatment success among people living with HIV and as a result mental health conditions among people living with HIV receive insufficient attention [61]. It is estimated that the prevalence of clinical depression is two-to-fourfold higher among people living with HIV compared to the general population or to people without HIV (for review, see [62]). The association between HIV infection and depression is complex and depression is both a risk factor for HIV infection, as well as a potential consequence [62]. A combination of risk factors, including social stressors and stigma, ART side-effects and comorbidities are thought to contribute to increased prevalence of depression among people living with HIV [62]. In addition, other mental health conditions, including anxiety, are reported among people living with HIV. One systematic review from 2014 which assessed the prevalence of depression and anxiety among people living with HIV on ART estimated that between 21% and 40% of people living with HIV on ART experience anxiety [61]. Other mental health conditions among people living with HIV include post-traumatic stress (PTS), which is defined as a lasting mental condition associated with exposure to a traumatic life event which individuals may re-experience [63]. HIV diagnosis is, for some, a traumatizing life event and it is documented that people living with HIV report relatively high rates of PTS [63].

1.3.6.4 Stigma

Besides various mental health concerns, HIV-related stigma is another significant psychosocial factor affecting the QoL of people living with HIV. Even today, more than three decades since the beginning of the epidemic, HIV-related stigma continues to affect prevention [64,65], treatment [66–68] and the lives of people living with HIV [69–73]. HIV-

related stigma is manifested by different mechanisms: stigma can be *anticipated, enacted and internalized* [74]. Anticipated stigma refers to expectations of prejudice, discrimination and stereotyping in the future by others because of one's HIV status. Enacted stigma refers to experience of prejudice, discrimination and stereotyping from others due to one's HIV status and internalized HIV stigma relates to the internalizing and endorsing of the negative beliefs and thoughts associated with HIV on oneself [74,75].

HIV-related stigma has been associated with a range of adverse health and social outcomes including depression, limited social support, lower QoL and poor physical health (for review, see [76]). The understanding of the mechanisms in which stigma is manifested and how it affects the health of people living with HIV is not fully understood, however it is suggested that different mechanisms of stigma may have different effects on health [75]. A recently published thesis examining contemporary experiences of HIV-related stigma in Sweden [77] concluded that despite the favorable medical conditions that Sweden offers, HIV-related stigma still prevails. The most common type of stigma reported among people living with HIV was disclosure concerns [71]. In addition, it was found that while people living with HIV who are virally suppressed did not necessarily experience enacted stigma, they still feared disclosure [77]. A qualitative study conducted in Sweden in 2017 found that people living with HIV who are virally suppressed experience HIV-related stigma in a complex way; although HIV had very little impact on participants' health, stigma still played a significant role on the participants' life [77].

There are numerous instruments used to assess HIV-related stigma [74]. According to a systematic review from 2016 [76], the most commonly used instrument to assess HIV-related stigma is the HIV stigma scale by Berger et al. [78], which is also used in the current study to assess four dimensions of stigma: personalized stigma, disclosure concerns, concerns about public attitudes and negative self-image [78].

1.3.7 Sexual health and sexual satisfaction among people living with HIV

HIV is a sexually-transmitted infection (STI) and that fact is particularly relevant in sexual situations. People living with HIV face various challenges related to their sexual life, which may in turn also affect overall QoL. Although viral suppression and significantly reduced risk of transmission as a result of effective treatment is the reality for many people living with HIV, fear of HIV disclosure and fear of rejection are some of the challenges people living with HIV face [33,34].

1.3.7.1 Disclosure of HIV status to sexual partners

According to the Swedish Communicable Disease Act, HIV is a notifiable disease and up until 2013, all people living with HIV were obliged to disclose their HIV status to sexual partners (see below “Medical and legal environment for people living with HIV in Sweden”). This legal obligation can have negative consequences for people living with HIV. A Swedish qualitative study from 2008 which explored how young adults living with HIV experience the Swedish Communicable Disease Act, found that people “turned off” their sexuality due to fear of disclosure and rejection [79]. It was previously found in Canada, where non-disclosure of HIV to sexual partners is also a criminal act, that this obligation negatively affected the possibilities of people living with HIV to have fulfilling sexual relationships [80]. Canadian qualitative studies [81,82] have found that, as a consequence of Canadian criminalization of HIV non-disclosure to sexual partners, some people living with HIV withdraw from sexual activity due to fear of HIV transmission, anxiety, uncertainty, fear of abandonment, and loss of ability to engage in fulfilling sexual relationships.

1.3.7.2 Sexual activity

Previous research found that sexual inactivity is frequently reported among people living with HIV [80,83–88] and is thought to be a coping strategy to deal with various challenges including HIV-related stigma and fear of HIV disclosure [80].

1.3.7.3 Sexual function

Another potential threat to the sexual health of people living with HIV is changes in sexual functions (desire, arousal and orgasm) [89–91]. This is similarly to sexual dysfunction in other chronic health conditions, such as diabetes, heart disease and urinary tract disorders [91,92]. The background to sexual dysfunctions is multifactorial where biological, emotional cognitive, interpersonal and contextual factors interact [91,93].

1.3.7.4 Sexual satisfaction

Due to the above-mentioned sexual challenges, a high proportion of people living with HIV report sexual dissatisfaction [80,83,84,86,87]. Studies comparing sexual dissatisfaction between people living with HIV and people without HIV found that dissatisfaction was higher in the former group [84].

Several sociodemographic and psychosocial factors have also been identified as contributors to sexual satisfaction among people living with HIV. These factors are also identified as being related to sexual satisfaction in various populations [7] and include unemployment [83,84], not having a steady relationship [83,94], low self-efficacy and social exclusion [86],

and feelings of loneliness [83,84]. Depression and anxiety were also found to be associated with sexual dissatisfaction [95] and with sexual functioning among people living with HIV [91].

1.3.8 Medical and legal environment for people living with HIV in Sweden

In Sweden, care for people living with HIV is free of charge and centralized to about 30 infectious disease clinics across the country. All people diagnosed with HIV are linked to specialized HIV care which include a team of specialist physicians, nurses and, most often, counsellors. ART is covered by the national health insurance and is free of charge upon prescription [18]. Generally, people living with HIV in Sweden with sustained viral suppression (95.3% of people living with HIV in Sweden in 2018 [15]), only need to visit their designated infectious disease clinic annually or biannually for routine check-ups.

1.3.8.1 The Swedish Communicable Disease Act

In Sweden, HIV is a notifiable disease and has been subject to mandatory partner notification since 1985, as regulated by the Swedish Communicable Disease Act (SFS 2004:168) [96]. Up until 2013, people living with HIV were obliged to disclose their HIV status to sexual partners, regardless of condom use or viral suppression status. However, adoption of the evidence of minimal sexual transmission risk in patients who are durably virally suppressed [97] has led to modifications in the application of this obligation. Since 2013, individual HIV-physicians have been able to exempt patients from disclosing their HIV status to sexual partners, provided that they fulfil the requisite criteria: adherence to medical visits and monitoring; sustained viral suppression (at least two repeated undetectable viral load measurements in the last 12 months; and unconditional condom use [97]. In practice however, additional exemptions are made in clinical practice, for example when discordant couples try to become pregnant. Despite the recent modifications, the law itself still exists and affects people living with HIV. The awareness of the modified implementation of the law is also insufficient among healthcare personnel as well as among people living with HIV. This was shown in a recent 2018 report by the Public Health Agency of Sweden (Folkhälsomyndigheten) which revealed that 57% of the 318 people living with HIV surveyed, had a conversation with their doctor about the possibilities of exemption and 39% received this exemption to disclose HIV status to sexual partners [98]. This implies that despite the fact that >95% of people who are living with HIV in Sweden are potentially eligible to be exempted from this legal obligation, not all benefit from this in practice.

1.3.8.2 The national HIV strategy

The National Strategy to combat HIV/AIDS and certain other communicable diseases (Government Bill 2005/06:60), adopted by the Swedish Parliament in 2006 has one main goal – “to restrict the spread of HIV infections and other sexually-transmitted and blood-

borne infections and to limit the consequences of these infections for society and the individual” [99]. The strategy was updated in 2016, due to the developments in effective treatment and the minimal risk of secondary transmission due to viral suppression [99]. One interim objective of the new strategy is to decrease HIV-related stigma and discrimination so that people living with HIV can disclose their HIV status without being discriminated against [99]. The strategy includes a new list of key populations who should receive extra attention both with regard to prevention and support. These key populations include men who have sex with men (MSM), people from high-endemic regions, people who inject drugs, trans people, young people and young adults and people in prostitution [99].

1.3.8.3 HIV Outcomes Initiative

The HIV Outcomes Initiative is a European organization, created in 2016 as a result of cooperation between European experts who wanted to direct policymakers and healthcare providers’ attention to the importance of various health issues and social exclusion of people living with HIV [100]. The initiative focuses on prevention and management of comorbidities and the need for patient-centered healthcare delivery as strategies to improve the long-term prospects of people living with HIV to live healthy, productive and rewarding lives [100]. The HIV Outcomes Initiative developed a set of recommendations for policymakers and the health community that include health–system- and policy-related strategies to improve the long-term health and wellbeing of people living with HIV [100].

Sweden is a part of this initiative and is often presented as a model country as regards the systematic and efficient monitoring of health and developments in patients living with HIV. Two well-cited examples are the national quality registry InfCare HIV and the delivery of cross-sectorial care to patients in, for example, the country’s second largest infectious disease clinic (Venhälsan, Södersjukhuset, Stockholm) [101].

1.4 TRANS PEOPLE

1.4.1 Important terms and definitions

Gender identity refers to a persons’ inner feeling of what gender they belong to [102] while gender expression is the outward presentation (clothes, hair, accessories, etc.) someone uses in order to be recognized by others as belonging to a certain gender [103]. Transgender (hereafter referred to as *trans*) is a self-defined umbrella term for people whose gender identity and/or expression differ from that assigned to them at birth [104]. Trans people may describe their trans experience as trans feminine, trans masculine, non-binary, crossdresser, or by other terms, see Table 1. In addition, trans people’s gender identity may be male, female, non-binary or other [105,106]. Some trans people have *gender dysphoria*. Gender dysphoria is distress caused by gender incongruence and one strategy to alleviate this is by gender-

affirming medical interventions such as hormone therapy and/or surgery [107]. However, not all trans people need or desire gender-affirming medical treatment [108,109].

Table 1. Glossary of trans-related terms that are mentioned in the thesis and in the individual papers

Asexual	<i>asexual</i> is usually used to describe a person who never or during some periods does not feel sexual attraction, does not have sex or does not want to include others physically in their sexual practice. ¹
Cisgender	A term used by some to describe people who are not transgender. "Cis-" is a Latin prefix meaning "on the same side as". ²
Cisnormativity	The assumption that all people identify themselves as the gender assigned to them at birth and live according to the gender social norms (feminine/masculine). ¹
Cross-dresser	The term <i>cross-dresser</i> is typically used to refer to men who occasionally wear clothes, makeup, and accessories culturally associated with women. ²
Gender dysphoria	Distress that gender incongruence might cause. ³
Gender expression	The way one expresses gender by use of certain clothes, hairstyles, accessories, make-up and other attributes. ³
Gender identity	A person's internal, deeply held sense of their gender. For transgender people, their own internal gender identity does not match the sex they were assigned at birth. ²
Gender incongruence	When a person's gender identity and/or expression does not align with the sex assigned to them at birth. ³
Gender Non-Conforming	A term used to describe some people whose gender expression is different from conventional expectations of masculinity and femininity. ²
Gender-affirming healthcare	Medical treatments aiming to alter the bodily characteristics in order to better align with the person's gender identity and ease gender dysphoria. Examples of gender affirming healthcare include hormone treatment, hair removal, vocal training and surgery. ³
Gender-affirming surgery	Surgeries aiming to change the body in different ways to better align with the person's gender identity. Examples may include breast augmentation, breast removal (mastectomy), creating new genitals, removing gonads, etc. ³
Heteronormativity	Denoting or relating to a world view that promotes heterosexuality as the normal or preferred sexual orientation. ⁴
Legal gender	The gender stated in legal documents, such as birth certificate and passport. Legal gender can, in some countries, be changed. Most countries only have two legal genders: male and female. ³
Legal gender recognition	The process in which a person's legal gender is changed to align with the person's gender identity. ³
Non-binary/genderqueer	A person identifying outside of the gender binary. Not identifying as male or female, perhaps being in between or a whole other gender. ³
Sex	The classification of a person as male or female. At birth, infants are assigned a sex, usually based on the appearance of their external anatomy. ²
Trans	Used as shorthand to mean <i>transgender</i> or <i>transsexual</i> - or sometimes to be inclusive of a wide variety of identities under the transgender umbrella. ²
Trans feminine	A person who was assigned male at birth, identifying or presenting as female or feminine. ³

Trans masculine	A person who was assigned female at birth, identifying or presenting as male or masculine. ³
Transgender	An umbrella term for people whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth. ²
Transphobia	An ideology or perception that expresses a strong negative view on transgender or persons whose gender expressions deviated from the norm. ¹
Transsexual	An older term that originated in the medical and psychological communities. ²
Transvestite	In the Swedish context, the term “transvestite” is a term often used by people who belong to this group themselves. The term refers to individuals who always or periodically express their gender differently from the sex assigned to them at birth. Many, however, do identify with their assigned sex at birth when they are not cross-dressed. ⁵

¹ RFSL. Glossary—Some LGBTQ terms and expressions explained. [Internet]. 2015. Available from: <https://www.rfsl.se/en/lgbtq-facts/lgbtq/glossary/>

² GLAAD. Glossary of Terms - Transgender [Internet]. Available from: <https://www.glaad.org/reference/transgender>

³ Zeluf G, Dhejne C, Orre C, Nilunger Mannheimer L, Deogan C, Höijer J, et al. Health, disability and quality of life among trans people in Sweden—a web-based survey. *BMC Public Health*. 2016;16(1):903.

⁴ Oxford Dictionaries. Definition of heteronormative in English:

⁵ Zeluf G, Dhejne C, Orre C, Mannheimer LN, Deogan C, Hoijer J, et al. Targeted Victimization and Suicidality Among Trans People: A Web-Based Survey. *LGBT Health*. 2018;5(3):180–90.

1.4.2 Prevalence of trans people and gender dysphoria

A systematic review from 2016 estimated the prevalence of self-identified transgender identity to be 0.3% (95% CI 0.1–0.6) [110]. Gender incongruence, defined as stronger identification with a different sex to the one assigned at birth, was estimated in the adult populations of Belgium and the Netherlands [105,111] to be 0.7–1.1% of assigned males and 0.6–0.8% assigned females at birth. Recently, a Swedish population study found that 2.3 % reported a feeling of gender incongruence measured in terms of the statement “I feel like someone of a different sex” [112]. In the same study, 0.6% of assigned males and 0.4 % of assigned females reported symptoms of gender dysphoria measured in terms of the statement “I would like hormones or surgery in order to be more like someone of a different sex” [112]. The prevalence of people who have undergone gender-affirming treatment and change of legal gender was estimated in Sweden in 2010 to be 1:15,047 assigned females and 1:8,636 for assigned males [113]. As a comparison, the Netherlands reported in 2015 the prevalence of people who have undergone gender-affirming treatment to be 1:5200 for assigned females and 1:2,800 assigned males [114].

Many countries have also reported an increase in people applying for gender-affirming healthcare [113]. The reason for this increase is unknown but reasons related to increased awareness and access to information, more tolerance in society, changes in diagnostic criteria, health care resources available and improved surgical outcomes, have been put forward as explanations [113].

1.4.3 Trans people's health

Trans people are a population disproportionately affected by adverse health outcomes. Health inequalities among trans people are multifactorial and, besides being characterized by common health determinants affecting the general population, are also heavily related to social and structural determinants [115]. Some health concerns are related to exposure to prejudice, stigma, discrimination and targeted victimization [115,116]. Trans people experience a high burden of violence and victimization, including sexual, physical, verbal and emotional violence [115]. These vulnerabilities are directly and indirectly associated with multiple adverse health outcomes including depression [117,118], sexual risk behavior and higher rates of HIV infection (mainly among trans women) [119–121], substance use [122] and suicidality [123,124]. The indirect health outcomes of stigma and discrimination may also include avoidant coping strategies which are related to depression [118] or postponing seeking health care when needed due to fear of discrimination [125]. Limited access to adequate, trans-competent and sensitive healthcare is another determinant which may lead to poor health outcomes [125–128].

Health concerns among trans people are also thought to be syndemic, i.e. health risks and adverse health outcomes are co-occurring and are largely determined by social inequalities [121]. These syndemics may include mental health conditions such as depression, violence and victimization, substance abuse and higher risk for STIs including HIV [121].

1.4.3.1 Gender-affirming healthcare

As mentioned earlier, not all trans people need gender-affirming care. In fact, a significant proportion of trans people report not needing medical gender-affirming interventions [129–131]. In a Canadian study of 433 trans people, 23% were living in their felt gender without any medical interventions [129]. Similarly, in a large American study, including 6,456 trans respondents, 18% reported living full time in accordance with their gender identity without medical interventions [131]. With that said, for trans people with gender dysphoria, gender-affirming medical intervention is essential in easing dysphoria and making the individual more gender congruent [132] and is therefore a key health determinant [115]. Access to gender-affirming healthcare varies tremendously between countries. In many countries, trans people are not recognized and in some countries trans people are even criminalized [133]. Besides juridical restrictions, gender-affirming health care depends on the fulfilment of specific treatment criteria, on health systems and health insurance coverage. In many countries, this type of healthcare is needed to be paid out-of-pocket and in other countries, strict gatekeeping might limit the access to needed healthcare [134]. Limited access to gender-affirming healthcare for trans people who need it may have negative social and health consequences including depression [135,136], increased discrimination [128], lower QoL [137] and increased suicidality [138]. Studies examining health outcomes in trans people after

undergoing gender-affirming interventions have found significant improvements in QoL [137], better self-esteem [139], higher job satisfaction, mental health and life satisfaction [140] and good physical and mental wellbeing [141].

1.4.3.2 Mental health

Given the above-mentioned vulnerabilities, it is not surprising that mental health is the most commonly studied research area of trans people's health [115]. Poor mental health, including depression and elevated suicide risk, is a commonly reported health concern among trans people [138,142–144]. Poor mental health is not always resolved by gender affirmation. This is supported in a large Swedish study from 2011 which investigated the rates of psychiatric morbidity and mortality among patients after gender-affirming surgery compared to matched controls [143]. The study found higher rates of death caused by suicide and cardiovascular diseases among patients who had undergone gender-affirming surgery [143]. This elevated suicidality could be explained by the fact that psychiatric morbidity is more prevalent among people applying for gender-affirming medical interventions [143]. While some psychiatric morbidity can be explained by gender dysphoria caused by gender incongruence per se, some are related to other challenges, that, if not addressed adequately, could remain even after gender-affirming treatment [145]. Studies have also found elevated rates of substance use among trans people [122].

1.4.3.3 Other health determinants

While certain health determinants are unique for trans people, most determinants are common for cisgender and trans people alike. However, some health determinants associated with poor health in the general population, such as unemployment and low income, may be elevated among trans people [146–148]. Age is another determinant of health which might be particularly important with regard to young trans people due to the increased vulnerability often reported among trans youth and young adults in particular with regard to exposure to victimization [149,150].

1.4.4 Quality of life among trans people

Earlier studies about the QoL of trans people suggest that factors related to mental health are associated with overall QoL [151]. The majority of studies addressing QoL among trans people focus on people who have undergone hormonal therapy or other gender-affirming healthcare interventions [137,152–155], in order to assess how these interventions improved QoL. A recently published meta-analysis found that, overall, trans people report poor QoL in all domains investigated, compared to the general population [154]. Another review assessing the QoL of trans people who received hormonal therapy and other gender-affirming therapies

found that 80% reported significant improvement in QoL after hormonal/medical interventions [137]. The positive effects of hormonal treatment on QoL was confirmed in another review [152]. A recent Swedish study which assessed QoL among trans women before and after gender-affirming surgery found that, overall, QoL improved one year after gender-affirming surgery [153]. The same study found that, while QoL improved, it was still lower compared to that of the general population [153]. Another study conducted among trans adolescents in Germany found that body dissatisfaction decreased QoL significantly as well as caused depression, anxiety and social withdrawal [155].

Other studies have suggested that the QoL of trans people compared to that of controls or the general population, is similar, with some exceptions related to worse sexual functioning and mental health among trans people [156,157]. Most studies mentioned above, however, have in common that they exclusively included trans people with gender dysphoria, who had undergone gender-affirming interventions or who were in the process of doing so and hence did not include self-identified trans people who represent different gender-affirming healthcare needs.

1.4.5 Sexual health and sexual satisfaction among trans people

According to a review of the global burden of disease among trans people, sexual health is the second most researched area in this population (after mental health) [115]. The majority of studies concerning sexual health, however, are focused on sexual health risk outcomes [115].

Trans women constitute a population which is disproportionately affected by alleviated rates of HIV [158,159]. The reasons behind this high vulnerability are thought to be driven by multiple factors including biological aspects related to excess risk of HIV transmission as a result of receptive condomless anal intercourse, network-related determinants including high rates of HIV and lack of knowledge about HIV-status within trans women's sexual networks, and structural determinants related to marginalization and discrimination of trans people. The latter determinants might limit the provision of important health and preventive services to trans people and might also lead some people to turn to sex work as a source of income [158]. Research also emphasizes how syndemic psychosocial health factors, such as depression, substance use, targeted victimization and internalized transphobia, may increase the risk of HIV and lead to worse HIV treatment outcomes [120,121]. Despite a large international body of research, the prevalence of HIV among trans people in Sweden is unknown.

In recent years, quantitative and qualitative studies have focused on other aspects of sexual health such as body and sexual satisfaction [160], sexual activity and sexual abstinence

[160,161], the effect of gender dysphoria on sexual health [162] and perceptions of trans people about their sexual health [163].

Trans people may face various challenges related to their sexual health. Fear of disclosing trans identity and fear of stigmatization and rejection in sexual contexts are some issues that affect the sexual health of many trans people [161]. It has also been indicated that trans people may feel objectified in some sexual situations, and treated with disrespect and prejudice in relationships due to their trans identity [161,163]. Studies suggest that gender dysphoria, body dissatisfaction and lack of access to treatment to ease this dysphoria may lead to sexual dissatisfaction [133,160,161,163]. Nikkelen et al. (2018) found that sexual feelings including sexual agency, sexual esteem and sexual pleasure were positively associated with body satisfaction [160]. Body dysphoria may also lead to trans people discovering their sexuality later in life [161,162]. Coping with body dysphoria may include imagining a different body, reinterpreting gendered body parts and by applying a gender role coherent with the gender identity in sexual situations [133]. Another strategy reported in the literature to cope with the various sexual challenges that trans people might face is sexual abstinence and a “turning off” of one’s sexuality [133,161,162]. These challenges and strategies may affect sexual satisfaction among trans people.

Another determinant of sexual health among trans people is hormone use. It is indicated that sexual desire increases among trans men who receive testosterone-derived hormones and to decrease among trans women due to use of estrogen-derived hormones [161,164]. One study did not find any relationship between sexual activity and hormone use, however, the authors suggested that this lack of association does not necessarily contradict effects on sexual desire [161].

It is also suggested that aspects related to minority stress, i.e. being subjected to prejudice, discrimination and targeted victimization, are relevant aspects that negatively affect the sexual health of gender and sexual minorities [165]. Various studies report high rates of sexual violence among trans people [166–168]. Sexual violence affects sexual satisfaction in a negative way through affecting sexual activity, function, desire and pleasure [169]. Besides aspects which are trans-related and which may affect sexual satisfaction among trans people, common sexual health determinants are equally important for trans people. These factors include being generally satisfied, having a partner and absence of depressive symptoms, among others [133,170].

1.4.6 Medical and legal environment for trans people in Sweden

1.4.6.1 Legal gender recognition

Sweden was the first country in the world to allow change of legal gender in 1972 [132]. The same law also regulates permission to undergo gender-affirming genital surgery (but not other gender-affirming treatments) [132]. To change legal gender and to obtain permission for gender-affirming genital surgery, a person has to be at least 18 years of age and felt for a long time like they belonged to the other gender, have lived according to that corresponding gender role (so called *real life experience*) and are likely to keep on living according to that gender role [132].

Up until 2013, legal gender recognition was possible if one was unmarried and a Swedish citizen [132]. Another requirement for legal gender recognition was that one had to undergo sterilization. This controversial requirement existed until 2013, when it was finally removed and people who apply for legal gender recognition are now offered fertility preservation prior to gender-affirming procedures [132]. In March 2018, the Swedish parliament took the decision to compensate trans people who had been forced to undergo sterilization between 1972 and 2013. Approximately 600–700 people are eligible for this compensation of EUR 22,500 [171]. Another change with regard to this regulation is that applicants no longer have to be unmarried or Swedish citizens. It is possible in Sweden to change legal gender to one of the two categories male or female [132].

1.4.6.2 Anti-discriminatory regulations

Other positive changes in recent years include the Discrimination Act (2008: 567) [172], which protects against discrimination in many areas, including healthcare, and which includes gender identity or expression as grounds for discrimination. In addition, the Government of Sweden has proposed legislative amendments that will enter into force the 1st of January 2019 and would mean that trans people would be afforded full protection under the hate crime legislation [173].

1.4.6.3 Gender-affirming healthcare in Sweden

In Sweden, gender-affirming healthcare is covered by the national health insurance and includes cross-hormone treatment, masculinization/feminization surgery, voice therapy and hair removal. In order to access gender-affirming health care in Sweden, a referral from a general practitioner or a psychiatrist is most often needed [174]. Once referral has been attained, special multidisciplinary gender teams are responsible for the assessment and diagnosis of gender dysphoria. These specialists are also responsible for the referrals of

medical procedures and for providing an assessment for the Legal Gender Advisory Board [174]. The process of evaluation in these designated clinics includes physical, psychological, psychiatric and social assessments. This whole process from receiving the referral to provision of gender-affirming care could take around six months but due to long waiting lists, two to three years is not uncommon. People who want to change legal gender and undergo gender-affirming treatment need to fulfil the legal prerequisite of living according to the gender role corresponding to their gender identity, the so-called ‘real life experience’, for a period of 12 months [174]. The process from being referred to a gender team and to completed change of legal gender could take between two to five years. Although the Swedish healthcare system provides gender-affirming treatments and surgeries without out-of-pocket expenditures, people who need access to these services often express frustration over the long waiting times and the long process that diagnosis and treatment entails. It is reported that these experiences of long waiting times to access trans-specific healthcare cause experiences of distress and anxiety [174].

The national guidelines for the evaluation and treatment of gender-affirming care were revised in 2015 by the National Board of Health and Welfare in the report “Good care of adults with gender dysphoria” [175]. These guidelines adopted some improvements in comparison with previous guidelines. For example, since 2015, the evaluation process is more flexible and individualized [132]. Previously, only trans people who received the diagnosis “transsexualism” could receive gender-affirming healthcare [132]. Since 2015, however, trans people who do not necessarily fulfil the criteria for “transsexualism”, including gender non-binary people, are offered care. Additional changes in the 2015 guidelines include: inclusion of some medical procedures that were previously excluded from the state funded care; and fertility preservation as an option prior to gender-affirming interventions [132].

1.5 CONCEPTS AND THEORIES

This thesis draws upon several concepts and theories, which are useful for understanding the complexity and interrelationships of factors that might affect health outcomes, including QoL and sexual satisfaction in the populations studied here. These theories were not necessarily used as an analytical tool in the individual studies, but elements of them were certainly used in the choice of variables to analyze and in interpreting our results as well as setting them in context. Below, the various concepts and theories relevant for this thesis have been listed.

1.5.1 Minority stress theory

The minority stress theory originates in the work of John Meyer (2003) who sought to explain the excess burden of mental poor health among sexual minorities through a process of accumulated social stress [176]. Meyer's theory extends on existing stress theories and argues that social stress is caused by conditions in the social environment as well as on a personal level. Meyer explains that people belonging to stigmatized social categories, including socioeconomic status, race, gender or sexuality, experience a strong impact of social stress. Minority stress refers to the social stress that stigmatized groups in society, often minority groups, experience: "The minority person is likely to be subject to such conflicts because dominant culture, social structures and norms do not typically reflect those of the minority groups" [176].

A minority stress is characterized by several conditions. According to Meyer, minority stress is something that is *unique*, *chronic* and *socially based*. This means that the stressors experienced by minority groups are *additive* to the common stressors that affect everybody (i.e. unique). In addition, these stressors are *chronic* in that they are experienced on a regular basis. Finally, these stressors are caused by *socially constructed* differences and barriers, institutions and social structures and are not biological determinants [176].

The minority stress model explains that minority stress occurs in a process of stress and stress-ameliorating factors on different levels:

- Exposure to proximal and distal minority stressors: distal stressors are experiences of rejection and discrimination while proximal stressors refer to the stress caused by the internalization of rejection and stigma;
- Stress-ameliorating factors: coping with and adaption and resilience to stigma. Group identity and solidarity on an individual level and group-level social structures can also have a buffering effect on stress;
- Stress and identity: group identities are essential for individual emotional functioning. The minority identity is something that could be emphasized and pointed out by others and cause distress to the individual who is identified as a minority. A minority identity is often also additive to other identities such as race and gender and these additive identities might cause aggregated stress.

When first developed by Meyer, the minority stress model sought to explain health disparities in *sexual* minority groups. However, in recent years the model has been used to explain health disparities among other groups, including trans people and people living with HIV. Testa et al. (2015), for instance, have adopted the minority stress model to trans people by

adding/adjusting some important elements specific for trans people. For example, distal stressors that, in the original model, include discrimination and violence apply to trans people as well. However, trans people may face an additional distal stressor according to the authors, namely “non-affirmation”. Non-affirmation refers to the disagreement between an individual gender identity/gender presentation and how this gender is perceived by others. The minority stress model has showed to be valid for explaining disparities in mental health inequalities among trans people [177].

When applying the minority stress model to gay and bisexual men living with HIV, Rendina et al. [178] explain that “*Similar to sexual minority stigma, HIV-related stigma operates through unjust social structures to negatively influence health. Similar to the evidence for sexual minority stigma, research shows that chronic exposure to HIV-related stigma might lead HIV-positive people to internalize negative messages about themselves and other HIV-positive individuals. Internalized HIV-related stigma has been associated with a range of negative mental health factors, including depressive symptoms, general psychological distress, low self-esteem, poor psychological well-being, and sexual compulsivity*” [178].

1.5.2 The socio-ecological model

The socio-ecological model was proposed by McLeroy et al. [179] who described it as a model for health promotion. The model was developed to explain how, in order to promote good health and healthy behavior, one cannot only consider individual behavior, but the interaction between individual and social environmental factors is also important.

The author explain that behavior is determined by multiple factors (Figure 2):

- **Intrapersonal factors** are factors which are individual and include knowledge, skills and attitudes;
- **Interpersonal factors** include the individual’s formal and informal relationships and their networks and social-support systems;
- **Institutional factors** include social institutions and rules and regulations;
- **Community factors** include relationship among organizations, institutions and informal networks within defined boundaries (including family and neighborhoods);
- **Public policy** refers to local and national policies and legislation.

Since it was developed in the late 1980s the socio-ecological model has been applied in understanding and conceptualizing various health and behavior aspects. It was applied in

physical activity behaviors [180], tobacco control research [180], to conceptualize HIV vulnerabilities [181] and sexual satisfaction [12], among others.

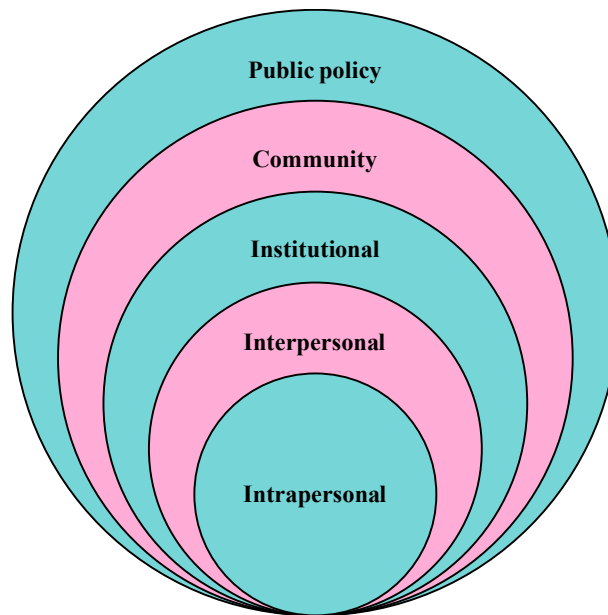


Figure 2. The socio-ecological model

1.6 RATIONELE FOR THE THESIS

Research evidence from different countries indicate that overall QoL and sexual health of trans people and people living with HIV is multifactorial and is largely associated with social and structural factors. The vast majority of people living with HIV in Sweden are durably virally suppressed and are expected to live a long life. In addition, the legal environment is changing and progressing thanks to the favorable treatment conditions bringing with it new implications regarding the implementation of the Communicable Disease Act. For trans people, legal structures are in place to protect against discrimination and medical guidelines are progressing to meet an increasing requirement for the individualized care of trans people with diverse treatment needs. Yet, up-to-date research concerning QoL and sexual health among trans people [153,163] and people living with HIV [71,72,182–184] is scarce in Sweden. The sexual aspect of health that is addressed in this project is a response to an increasing need for a rights-based approach to sexual health which adopts the understanding that various populations are less likely to enjoy these rights.

2 AIMS AND OBJECTIVES

The aim of this thesis was to explore quality of life (QoL) and sexual health as well as the associated factors thereof among trans people and people living with HIV. The overall goal was to identify needs and strategies that can enhance and support good living conditions among trans people and people living with HIV in Sweden today.

The specific objectives were:

- I. To identify factors that are associated with QoL among people living with HIV
- II. To explore sexual satisfaction and its contributors among people living with HIV
- III. To examine factors associated with self-rated health and QoL in a population of self-identified trans people
- IV. To examine factors associated with sexual satisfaction in a population of self-identified trans people

3 METHODS

3.1 SUMMARY OF STUDIES INCLUDED IN THE THESIS

This thesis is based on two large surveys and cohorts: ‘Living with HIV’ was a nationwide survey conducted in 2014 and explored QoL in a representative population of people living with HIV (Paper I & II). ‘Health for all’ was a web-based survey conducted in 2015 and targeted people self-identifying as trans. The survey explored various aspects of health and QoL (Paper III & IV). Table 2 below illustrates the studies, study populations and data-collection methods included in this thesis.

Table 2. Summary of the papers included in the thesis

Paper	Study population	Research question	Study design	Main analysis
I	People living with HIV (n=1096)	What socio-behavioural, clinical, psychological, sexual, social support and personal components are associated with overall QoL among people living with HIV in Sweden?	Quantitative cross-sectional, nationwide survey	Logistic regression analysis
II		What factors are directly and indirectly associated with sexual satisfaction among people living with HIV?		Path analysis
III	Trans people (n=796)	What factors are associated with the self-rated, self-reported disability and QoL among self-identified trans people in Sweden?	Quantitative cross-sectional, web-based survey	Logistic regression analysis
IV		<p>i. What proximal and distal factors are associated with sexual satisfaction among self-identified trans people in Sweden?</p> <p>ii. What characterize self-identified trans people’s sexual practice and needs for sexual health services?</p>		

3.2 LIVING WITH HIV (PAPER I & II)

3.2.1 Survey development

During 2013-2014, the Public Health Agency of Sweden financially supported a nation-wide study aiming to explore QoL among people living with HIV in Sweden. The study consisted of an anonymous, self-reported questionnaire. The questionnaire was developed and extensively piloted in close collaboration with healthcare partners and three large HIV-organizations in Sweden: HIV-Sweden, Riksförbundet Noaks Ark (National HIV Association Noah's Ark) and Stockholms Brukarförening (Stockholm's Drug Users Union), in order to make the questions as relevant as possible. Participating clinics were invited to give feedback about the questions before the questionnaire was piloted (the questionnaire is available in a published report [185]).

3.2.2 Data collection procedures

All 30 infectious disease clinics across the country were invited to participate in the data collection and 15 clinics agreed to do so. In addition, two needle exchange programs based in Stockholm participated in data collection (Appendix 1) in order to reach people who inject drugs. In total, 17 sites participated in the data collection, representing 75% of all (at the time of data-collection) known HIV patients in the country. The desired sample size was calculated previous to data collection based on the national quality HIV-care registry InfCare HIV, where all known people living with HIV are registered [15]. It was decided to target 15–20% of the total number of patients with HIV at each data-collection site/clinic. A consecutive recruitment of people living with HIV was conducted by offering the questionnaire to patients visiting their assigned healthcare facility for a routine visit during the data collection period (December 2013-August 2014) excluding patients <18 years of age and who were newly diagnosed (<6 months prior to the study).

Eligible patients visiting their designated clinics for routine visits were asked by the study's different contact persons (nurses, doctors and counsellors) at each clinic if they wanted to participate in the study. In addition, information about the study was distributed through the collaborating HIV-organizations, through posters at infectious disease clinics across the country (Figure 3) as well as on the study's website (www.attlevamedhiv.se) which informed about the survey in the different languages the survey was available in (specified below, under 'Survey administration'). At two infectious disease clinics in Stockholm (Huddinge and Venhälsan), that together account for >60% of the proportion of outpatients across the country, a group of three research assistants were on-site during designated times during the weeks of data-collection, in order to recruit patients. To monitor data collection progress, one research assistant was designated to have oversight of all data-collection sites across the country.

In order to ensure the recruitment of a valid study population, contact persons at each site were asked to keep a log of the number of people who were asked to participate and who agreed and declined participation based on gender, approximate age, born in Sweden/ abroad and assumed route of transmission for each participant/non-participant. For various reasons, including limited time for the health workers/contact persons to fill in the reports, and hesitation about filling in the logs without revealing identifying details that could jeopardize patient integrity and confidentiality, log lists on participants/non-participants were filled in inconsistently (see also “Methodological discussion”). While some data collection sites had regularly kept log lists about outpatient participations, other sites sent incomplete lists. These inconsistencies undermined our ability to conduct a non-response bias analysis and to estimate the response rate. However, thanks to the national quality registry system of all people living with HIV in Sweden, InfCare HIV, we can estimate the rates of participation according to some sociodemographic characteristics (i.e. sex, age, mode of HIV transmission, and country of birth). From the sites that had consistently filled in the log lists, the participation rate was 70%. These sites however are not representative of the whole country since they are located in smaller counties with fewer patients. At other sites, the participation rate varied from 37% (Huddinge, Karolinska University Hospital the largest data collection site) to 57% (Skåne University Hospital, Malmö, the third largest data collection site). Some trends could be identified from the log list reports: women, more often than men, declined participation or did not send the completed questionnaire after agreeing to participate. In addition, people born outside Sweden and whose mode of HIV transmission was heterosexual sex seemed to be less likely to participate compared to Swedish-born non-heterosexuals.



Figure 3. The “Living with HIV” survey’s logo

3.2.3 Survey administration

The final questionnaire included 77 items. The questionnaire covered information on sociodemographic characteristics, HIV-related physical, psychological and sexual aspects, getting older with HIV, being able to travel, satisfaction with HIV care, social support and quality of life. To reduce the risk of underrepresentation of migrants, the questionnaire was made available in 10 languages: Swedish, English, French, Spanish, Russian, Thai, Somali, Amharic, Arabic, and Tigrinya. Those who could not fill out the questionnaire in any of the languages or those with reading and writing difficulties who wanted to participate were offered to have the questions read to them by a telephone interpreter in a confidential setting at the respective collaborating infectious disease outpatient clinic. However, none of the participants chose this service.

During the recruitment period, outpatients living with HIV visiting their infectious disease clinics were informed about the study and invited by a site coordinator to anonymously participate in the study by completing a questionnaire in their language of choice. Participants in the study were not offered any compensation but the purpose and the importance of the study were explained to them. Participants could complete the questionnaire in a confidential setting at their outpatient clinic, put the questionnaire in a sealed envelope, and drop it in a locked box. Alternatively, participants could choose to complete the questionnaire at home and mail it in a pre-stamped envelope to the research team at Karolinska Institutet (for information given to participants, see Appendix 2). The site coordinator collected the sealed envelopes and sent them to the research team at the Karolinska Institutet. Completion of the questionnaire took between 20 and 40 minutes.

3.2.4 Dependent variables

In Paper I, QoL was assessed by a single item, asking participants to rate their QoL on a visual analogue scale (VAS) ranging from 0 (very poor QoL) to 10 (very good QoL). For analyses, the variable QoL was used as an ordinal variable with 11 categories.

In Paper II, to assess sexual satisfaction, one item from the Life Satisfaction checklist (LiSAT) was used [186]. Participants were asked to rate their level of satisfaction with their sex life with the help of a six-point scale. The question was formulated as follows: “With my sex life I am... ” (“very dissatisfied”, “dissatisfied”, “rather dissatisfied”, “rather satisfied”, “satisfied”, “very satisfied”). We chose a cut-off at “rather dissatisfied”, which was coded as *dissatisfied*. The sexual satisfaction scale was thus dichotomized (satisfied/dissatisfied) for analyses.

3.2.5 Study respondents

In total 1,100 people responded to the survey “Living with HIV”. However, not all respondents were included in the respective analyses in Paper I and Paper II. Four respondents (n=4) were removed from further analyses based on them not meeting the inclusion criteria (having received their HIV diagnosis <6 months prior to recruitment). After removal of these respondents, the total number of respondents was 1,096. In Paper I, we excluded 10 respondents who did not report their gender, leaving a study population of 1,086 respondents. In Paper II, 14 respondents were excluded from analyses. Since the analysis of sexual satisfaction was gender-dependent, respondents who did not report their gender (n=10) and who reported “other” gender identity (n=4) were removed from analyses.

3.2.6 Statistical analysis

In Paper I, we identified contributors associated with self-reported QoL by employing descriptive statistics, univariate and multivariate ordinal logistic regression analysis. Significant ($p \leq .05$) variables from univariate analyses and other considered important control covariates (gender, age, birth origin, level of education, sexual orientation and time since HIV diagnosis) were later included in a multivariate ordinal logistic regression analysis. The measures of association are presented as crude and adjusted odds ratios (OR/aOR), with 95% confidence intervals (CI). A non-response or the response “do not want to answer” on considered sensitive items, such as sexual orientation, HIV transmission route and injecting drug use, were coded as ‘missing/do not want to answer’. Otherwise, to manage missing data, we conducted multiple imputation using chained equations [187]. For the estimation of the analysis, twenty imputed datasets were used. In the imputation modelling, logistic regression was used for the binary variables, ordinal logistic regression for the ordinal variables, multinomial logistic regression for the nominal variables, and linear regression for the continuous variable. The dependent variable was also included in the imputation modelling, but excluding observations with missing values [188]. Stata version 13.1 (StataCorp LLC, College Station, TX) was used for all analyses in Paper I.

In Paper II, we investigated direct and indirect paths of associations between various variables and sexual satisfaction by applying a path analysis. The analyses included four stages. First, we analyzed the data descriptively. Secondly, we conducted univariate analyses of covariates of interest (Table 3) and the outcome sexual satisfaction and identified significant variables. Significant variables from univariate analyses ($p \leq .05$) were then included in multivariate logistic regression. In the third stage, in order to assess potential, indirect contributors to sexual satisfaction, each significant variable from the previous stage (multivariate analysis) was treated as a dependent variable and all covariates from the first stage (univariate analysis) as independent variables. We applied univariate logistic regression for categorical variables and univariate linear regression for continuous variables. Significant

independent variables from univariate analyses were then included in multivariate linear or logistic regression models. All analyses of male participants were adjusted by self-reported sexual orientation. In addition, for all univariate and multiple analyses with categorical outcomes, we calculated OR and 95% CI. The last stage of analysis included fitting two path models, one for male participants and one for female participants and evaluation of direct and indirect paths between covariates and sexual satisfaction. To estimate model fit, full models were compared to null models using the likelihood difference test, where -2 times the log likelihood difference is distributed as chi-square (Browne &, Cudeck, 1993), and differences in Akaike Information Criteria (AIC) and Bayesian Information Criteria (BIC).

To manage missing data, we conducted multiple imputation. Imputation for variables with missing values was conducted using Bayesian analyses [190]. Ten imputed datasets were used in the estimation of all analyses using maximum likelihood estimation. Maximum likelihood parameter estimates for each analysis were averaged over the set of 10 analyses and standard errors were computed using the average of the standard errors of the analyses and the between analyses parameter estimation. The statistical analyses were performed with MPlus version 7.4 [191].

In both studies (Paper I & II), independent variables were clustered into components. In Paper I, independent variables were grouped into sociodemographic, behavioral, clinical, psychological, sexual life, social support and personal resource components. In study II, independent variables included in the analyses were clustered into four components: the sociodemographic, the clinical HIV-related, the psychological, and the sexual component. Analyzed covariates were coded differently depending on the statistical analysis performed. In Paper I, covariates were mostly categorical while in Paper II they were dichotomous. Table 3 below illustrates the independent variables from Paper I &II, how they overlap and how they differ.

Table 3. Covariates included in Paper I and Paper II

Variable Paper I Outcome: QoL	Variable Paper II Outcome: sexual satisfaction	Coding method/comments
<i>Sociodemographic component</i>		
Gender		the alternative “other” in Paper I was kept despite few observations
Male	Male	
Female	Female	
Other	-	
Age (years)		
Birth origin		

Sweden	Sweden	
Outside Sweden	Outside Sweden	
Employment		Dichotomised from originally ‘choose all that apply’-item with 15 alternatives listing different occupations
Working/studying	Working/studying	
Unemployed/long-term sick leave	Unemployed/long-term sick leave	
Education		Condensed into fewer categories from originally six alternatives representing length of education in years
0–9 years	-	
10–12 years	<12 years	
>12 years	>13 years	
Monthly income	-	Dichotomised from seven self-reported income alternatives
Middle/high-income		
Lower income		
Sexual orientation		Condensed into fewer categories from originally five alternatives. In Paper I, we kept the missing observations and the response alternative “Do not want to answer”
Heterosexual	Heterosexual	
Non-heterosexual	Non-heterosexual	
Do not want to answer/missing	-	
Relationship status		
Partner	Partner	
No partner	No partner	
Homelessness past 6 months	-	
Smoking	-	
Non-smoker		
Former smoker		
Current smoker		
Drug use past 6 months	-	
No drug use		
Drug use		
Do not want to answer/missing		
Alcohol consumption	-	Variable is based on three items summed into a scale, analysed according to the Alcohol Use Disorders Identification Test (Audit-C) [192]
Non-hazardous consumption		
Hazardous consumption		
Clinical component		
Time since HIV diagnosis		
< 1–5 years	-	Condensed into fewer categories from originally six response alternatives representing time since diagnosis
5–10 years	<10 years	
> 10 years	>10 years	
Mode of HIV transmission	-	In Paper I, we kept the missing observations and the response alternative “Do not want to answer”
Heterosexual contact		
Sex between men		
Injecting drug use		
Mother-to-child transmission		

Blood		
Other		
Missing/do not want to answer	-	
Comorbidities	-	Dichotomised based on reporting one or more of seven disease alternatives or stating “no” on an item about co-diseases
Yes		
No		
HIV-related physical symptoms	-	
Yes		
No		
Don't know		
Side-effects from ART		In Paper I the variable is based on two items concerning: (1) experiencing of side-effects from ART and (2) whether one is bothered by these side-effects. In Paper II the variable is only based on the first question
Yes	Yes	
No	No	
Psychological component		
Hopelessness		The variable is analysed using the Beck Hopelessness Scale [193] which includes 20 true/false statements
Absent	Absent	
Mild	-	
Moderate-severe	Mild-moderate-severe	
HIV-related stigma		The variables were analysed using 12 items based on the 12 items Swedish short-form version [194] of the HIV Stigma Scale [78]. The instrument produces three sub-scales. In Paper I, each stigma variable was divided to 3 categories representing different levels of stigma while in Paper II, only two dimensions (sub-scales) of stigma were analysed and each sub-scale was dichotomised.
Personalised stigma	-	
Lower stigma		
Fairly high stigma		
Higher Stigma		
Negative self-image		
Lower stigma	Lower stigma	
Fairly high stigma	-	
Higher Stigma	Higher Stigma	
Concerns with public attitudes		
Lower stigma	Lower stigma	
Fairly high stigma	-	
Higher Stigma	Higher Stigma	
Disclosure concerns	-	
Lower stigma		
Fairly high stigma		
Higher Stigma		
Satisfaction with HIV disclosure	-	
Satisfied		
Would like to be more open		
Would like to be less open		
Do not want to answer		

-	HIV-related PTSD symptoms	Variable is based on 15 items composing the Impact of Event Scale [195]
	Absent	
	present	
<i>Sex-life component</i>		
	Sexual satisfaction	One item from the Life Satisfaction checklist [186]. In Paper I, sexual satisfaction is an independent variable and in Paper II the dependent variable
Satisfied	Satisfied	
Dissatisfied	Dissatisfied	
	Changes in sex life due to HIV	In Paper I, we kept the missing observations and the response alternative “Too personal/cannot decide”
No change	No change	
Positive change	Positive change	
Negative change	Negative change	
Too personal/cannot decide	-	
-	Sex in the past 6 months	
	Yes	
	No	
-	Importance of sex	Dichotomised from originally four response alternatives
	Very or fairly important	
	Not very important or not important at all	
-	Sexual desire in the past 6 months	Dichotomised from originally four response alternatives
-	Yes	
-	No	
-	Sexual pleasure in the past 6 months	Dichotomised from originally four response alternatives
-	Yes	
-	No	
-	For male respondents: Erectile difficulties	Dichotomised from originally five response alternatives
	Never or rarely	
	Sometimes, often or always	
-	For male respondents: Distress due to erectile difficulties	
	No distress	
	Minor or major distress	
-	For female respondents: Orgasmic difficulties	Dichotomised from originally five response alternatives
	Never or rarely	
	Sometimes, often or always	
-	For female respondents: Distress due to orgasmic difficulties	Dichotomised from originally three response alternatives
	No distress	
	Minor or major distress	
-	For male respondents: Ejaculatory difficulties	Dichotomised from originally five response alternatives
	Never or rarely	
	Sometimes, often or always	
-	For male respondents: Distress due to ejaculatory difficulties	Dichotomised from originally three response alternatives
	No distress	

	Minor or major distress	
	Obligation to disclose HIV status an obstacle to look for a long-term partner	Dichotomised from originally three response alternatives
-	Definitely or to a certain extent	
	Not at all	
<i>Social support component</i> -		
HIV-related support		Dichotomised from originally six response alternatives
Have HIV-related support		
Have limited HIV-related support		
<i>Personal resource component</i>	-	
Change in perceived self-esteem due to HIV		
No change		
Positive change		
Negative change		
Meaningful life after HIV diagnosis		
Life is as meaningful		
Life is more meaningful		
Life is less meaningful		

3.3 HEALTH FOR ALL (PAPER III & IV)

3.3.1 Survey development

During the autumn of 2014, the Public Health Agency of Sweden initiated a study exploring the health situation and health determinants of trans people. This study was commissioned as a part of the Public Health Agency's mandate to analyze health and health determinants routinely among lesbian, gay, bisexual, trans and queer (LGBTQ) persons [196].

The survey was developed by researchers at Karolinska Institutet in collaboration with the Public Health Agency of Sweden, the Swedish Federation for Lesbian, Gay, Bisexual, Trans and Queer (LGBTQ) Rights (RFSL) and the Swedish Youth Federation for LGBTQ Rights (RFSL Ungdom). In addition, several expert group meetings took place with trans people, trans organizations, with specialists working clinically with trans people and with different governmental agency who in different ways work with relevant trans-related topics. These meetings were organized not only for the development of the questionnaire but also for consultation about the dissemination of results once data was collected.

The final survey was administrated on the web and included 106 questions (including skip questions) covering eight main themes; sociodemographic background, general health, wellbeing, gender-affirming treatment, life-style habits, experience of victimization and

social support networks, sexual life and QoL. It took between 20-40 minutes to complete. The survey included some questions previously included in Swedish population health studies for comparison purposes. Trans-specific questions were developed by the research team or were partly based on surveys conducted in other countries (the questionnaire is available in a published report [196]). The survey was pilot-tested with six trans-identified individuals and revised accordingly before being finalized.

3.3.2 Data collection procedures

Data was collected via an anonymous, self-selected web-based survey, carried out between September and November 2014. Convenience sampling was used to recruit participants since the trans population is of an unknown size and hard to reach via means of random sampling. In this study, participants were recruited through email invitations by Scandinavia's largest online community for LGBTQ people, Qruiser (<https://www.qruiser.com>), as well as by advertisements on the same website. Qruiser sent reminders to trans members who did not open the link to the survey one week after the first message was sent out. Other large LGBTQ organizations promoted the study via different social media channels and personal invitations. In addition, clinics specializing in gender-affirming related care received information about the study and were encouraged to inform their patients. Advertisements about the survey were also made online, via Google AdWords. Individuals aged >16, who live in Sweden, speak Swedish and identified as being or ever being trans were eligible to participate in the study.

Data collection was regularly monitored and reported to the research team in order to optimize the number of responses and the channels of recruitment. Since there was no pre-determined sample size, it was decided to set a date for the last day of data collection which was the end of October 2014 (two months in total). Our guiding assumptions about optimal sample size were made according to previously conducted studies with similar methodology which reached 300-400 respondents [197,198], and our goal was therefore to reach approximately 400 respondents by the end of data collection. Oversight of data collection included daily monitoring of the link to the web-survey to make sure there were no technical issues, registering the number of daily respondents to the web-survey and contacting collaborating organizations about sending reminders and messages about the survey.

3.3.3 Survey administration

The survey was administrated online, via an URL link that was distributed via various online channels (described above, under 'Data collection procedures'). The survey was constructed

using LimeSurvey, which is electronic web-survey software. In order to complete the survey, respondents were asked to click “I agree” on an electronic consent form (Appendix 3).

3.3.4 Dependent variables

Dependent variables in Paper III were QoL, self-rated health and self-reported disability. QoL was assessed, similarly to Paper I, using a single question asking participants to rate their QoL on a visual analogue scale ranging from 0 (very poor QoL) to 10 (very good QoL). For the purpose of analysis, we dichotomized the outcome QoL by making an arbitrary cut-off at the median score of the scale (=6).

Self-rated health was measured by the question: “How would you assess your general health?” The variable was categorized into good (“very good” and “good”), fair self-rated health (“fair”) and poor (“poor” and “very poor”).

Self-reported disability was defined by the answers: (1) “Yes, to some extent” or, (2) “Yes, to a high extent” to the question “Do you have any physical or mental condition that impairs your work ability or hinders you in your everyday life?”

Sexual satisfaction, the dependent variable in Study IV, was assessed using the same instrument, LiSAT, as in Paper II (see above) [186]. We chose a cut-off at “rather dissatisfied” and coded that response as “dissatisfied”. The sexual satisfaction scale was thus dichotomized (satisfied/dissatisfied) for analyses.

3.3.5 Study respondents

In total, 796 eligible respondents completed the survey included in Paper III and IV. In Paper III, all 796 respondents were included in the analysis. In Paper IV, however, the analysis is based on 595 respondents. Participants who had never had sex were removed from the analysis (n=76), in addition to respondents who did not complete the voluntary section of the questionnaire concerning gender-affirming healthcare (n=110). Fourteen more individuals were excluded due to missing values on the selected variables.

3.3.6 Statistical analysis

In Paper III, descriptive analyses (frequencies) were carried out to describe the characteristics of study participants and univariate and multivariate analyses were performed for each respective health outcome (i.e. self-rated health, self-reported disability and quality of life) for all variables of interest. For the outcome self-rated health, ordinal logistic regression was used and for the outcomes quality of life and self-reported disability, logistic regression was used. The measures of association are presented as crude and adjusted OR, with 95 % CI.

Three backward selection models were performed, one for each health outcome, in order to identify significant variables for each respective outcome. A Wald's test was used for variables with more than one category in univariate and multivariable analyses, in order to assess significance of the variable as a whole. Stata, version 13.1 (StataCorp LLC, College Station, TX) was used for all analyses in Paper III.

In Paper IV, descriptive analyses were performed by computing frequencies of target variables. In order to assess multicollinearity, variance inflation factors (VIF) and a tolerance test were executed by examining all the variables of interests. Multicollinearity was not identified in the data judging from VIF values of below 4.0 and a tolerance level of less than 0.2 [199]. Logistic univariate regression analyses were performed between the dependent variable sexual satisfaction and each of the explanatory variables listed below (Table 4). Variables with a p-value <0.2 in the univariate analyses and those considered to be relevant (sexual violence) were later included in the multivariate logistic regression analysis. Variables with a p-value <0.05 were considered statistically significant in multivariate analysis. The measures of association are presented as crude and adjusted OR, with 95% CIs. All analyses in study IV were executed using Stata version 15.1 (StataCorp LLC, College Station, TX).

The independent variables included in Paper III and IV are detailed in Table 4.

Table 4. Covariates included in Paper III and Paper IV

Variable Paper III Outcome: QoL	Variable Paper IV Outcome: sexual satisfaction	Coding method/comment
Trans experience		Variable composed of two items regarding gender identity and trans experience. In Paper III we use the self-identified term “transvestite” and in Paper IV we use the term “cross-dresser”
Trans feminine	Trans feminine	
Trans masculine	Trans masculine	
Gender non-binary	Gender non-binary	
Transvestite	Crossdresser	
-	Sexual orientation	Variable dichotomised from originally nine alternatives and composed of “check-all –that- apply” question
	Homosexual/heterosexual/asexual	
	Other	
Age (categories)	Age (years)	
16–19		
20–29		
30–44		
45–64		
65–94		
Country of birth	-	
Sweden		

Other than Sweden		
County	-	Dichotomised from 21 response categories listing the different Swedish counties
Large county (< 500,000 inhabitants)		
Small county (> 500,000 inhabitants)		
Employment status	-	Dichotomised from originally 'choose all that apply'-item with nine alternatives describing different occupations
Working/Studying		
Unemployed/long-term sick leave		
Retired		
Other		
Education	-	Condensed from originally eight alternatives representing different types of education
No high school education		
Upper-secondary education, or some university		
University education ≥ 3 years		
Other		
Monthly net income (€)	-	
0–1416		
1417–2125		
2126–3238		
>3239		
Tobacco use ever	-	Originates from two items about the use of snuff or cigarette smoking. Used to (smoke or use snuff) but quit, is coded as 'yes'.
Yes		
No		
Alcohol risk consumption	-	Based on one item about the number of drinks consumed on a typical drinking session. ≥ 5 drinks was considered risk consumption
Yes		
No		
Illicit drug use (6 months)	-	
Yes		
No		
Do not want to answer		
Religiosity	-	Dichotomised from originally four response alternatives
Yes		
No		
Self-rated health		The variable self-rated health was a dependent variable in Paper III and an independent variable in Paper IV
Good	Good	
Fair	Fair	
Poor	Poor	
-	Negative mood symptoms	Condensed from originally five response alternatives concerning how often one had felt unhappy during the past weeks

	Yes	
	Sometimes	
	No	
-	Offensive treatment	Based on two items on (1) experience of offensive treatment in the past 12 months, and (2) the reasons for being offended. If the reasons included 'gender' or 'gender identity/expression', variable was coded as 'yes'
	Yes	
	No	
-	Sexual violence	
	Yes	
	No	
Gender legal recognition		
No, and do not need to	No, and do not need to	
Yes	Yes	
No, but would like to	No, but would like to	
No, and cannot change legal gender because the desired gender is not available in Sweden today	No, and cannot change legal gender because the desired gender is not available in Sweden today	
Do not want to answer	-	
-	Need for gender-affirming healthcare	assessed by two questions: (1) "have you ever sought professional help to get a referral to gender-affirming healthcare?" ,and: (2) "have you ever received a referral to gender-affirming healthcare?"
	No need	
	Need unfulfilled	
	Need (partly) fulfilled	
-	Hormone use	Analysed as an interaction term together with the variable 'sex assigned at birth'
	Yes	
	No	
-	Living according to gender identity	Dichotomised from originally four response alternatives
	Yes	
	No	
Openness with trans identity		
-		
Always open		
Sometimes open		
Rarely open		
Never open		
Trans identity shows		
History of negative health care experiences	-	dichotomised from multiple responses to the question: "Have you experienced any/some of the following events when you encountered the health care system?"
Yes		
No		
Practical support		
-		
Always		
Most of the time		
Almost never		

Never		
Social support		
Yes	Yes	
No	No	
-	Number of sexual partners last 12 months	
-	Current sexual partner	
	Yes, one	
	Yes, several	
	No	
-	Relationship satisfaction	
	Satisfied	
	Dissatisfied	
	Have no relationship/missing	
-	History of sex in exchange for money	Dichotomised from originally four response alternatives
	Yes	
	No	
-	Possibilities to discuss sexual matters with healthcare	Condensed from originally six response categories
	Yes	
	Doubtful	
	No	

4 ETHICAL CONSIDERATIONS

4.1 ETHICAL PERMITS

Both studies included in this thesis had ethical permits. The study ‘Living with HIV’ (Paper I & II) was approved by the Regional Review Board in Stockholm (DNR 2013/1552-31/4) and the study ‘Health for all’ (Paper III & IV) was approved by the Regional Review Board in Stockholm (DNR 2014/857-31/5).

4.2 INFORMED CONSENT

Informed consent was obtained for both studies:

In the study ‘Living with HIV’ (Paper I & II), participants received written information about the study, including information about the nature of the questions and the fact that participation in the study was anonymous and voluntary (Appendix 2). At the end of the information text provided in the questionnaire, participants were informed that by responding to the questions, they were consenting to participation.

In the study ‘Health for all’ (Paper III & IV), which took the form of a web-based survey, participants received information about the study electronically, when clicking on the link to the web-survey. The electronic information page explained the purposes of the study and who participants could contact in case of questions and where they could turn to if they needed support. Participants were also informed that their participation was voluntary and anonymous. At the end of the information page, participants were asked to give their consent by clicking “I agree” to the statement: “I have received written information about the study ‘Health and life situation for transgender people in Sweden’ and agree to participate in the study. I know my involvement is voluntarily and that my answers are completely anonymous” (Appendix 3).

4.3 PRIVACY AND CONFIDENTIALITY

Data collection procedures were completely anonymous and there is no risk for identification of individuals in the way data is presented. For Paper I & II, participants could answer the questionnaire in the privacy of their home and send their completed questionnaire by pre-stamped post or by sitting in a quiet and private space in the clinic which they were visiting. Despite anonymity and flexibility as to where to fill in the questionnaire, many respondents chose to complete the questionnaire in Swedish and not in their mother tongue (Table 5) and none of the respondents used the services of a translator. In addition, nearly 13% did not report their country of birth, which implies that some participants did not fully trust that their

answers were completely anonymous and our general impression was that reluctance to reveal country of birth/choose questionnaire in the mother tongue was related to stigma and fear of being identified. For Paper III & IV, the survey was completed online and there was no interaction between participants and data collectors. Participants could answer the questionnaire on their computers and in their own time.

Table 5. Proportion of questionnaires taken in the different languages offered (Paper I & II)

Language	n (%)
Amharic	12 (1)
Arabic	8 (1)
English	86 (8)
French	18 (2)
Russian	8 (1)
Somali	4 (0.3)
Spanish	9 (1)
Swedish	895 (82)
Thai	40 (4)
Tigrinya	16 (1)
Total	1,096 (100)

5 MY ROLE IN THE PROJECTS' DIFFERENT PARTS

5.1 DATA COLLECTION, DATA ANALYSIS AND RESULTS DISSEMINATION PAPER I & II

I became involved in the project 'Living with HIV' (Paper I and II) from the early phases of data collection. I joined the project as a research assistant and my role was to, together with two research assistants, recruit patients visiting the infectious disease clinic in Huddinge (Karolinska University Hospital) and to have oversight of the collected questionnaires from the different data-collection sites. At a later stage, I was also responsible, together with another research assistant, for data entry from all surveys. I was thus familiar with the data from the early stages of data collection and my interaction with patients at the clinic also made me aware of different aspects of the data collection procedures.

I executed the preliminary data analysis including data cleaning and coding. Main data analysis was mostly conducted by a statistician (Jonas Höijer), however I was involved in all stages of data analyses from data preparation to planning and executing the analyses. For study II, where I am the second author, the main data analysis was conducted by a statistician and by the first author, Lena Nilsson Schönnesson. My involvement included, in addition to preliminary data analysis, the interpretation of results and drafting of the manuscript. Naturally, I was also heavily involved in manuscript preparations from the derived data. In Paper I, I was the corresponding author and in Paper II, I was heavily involved in manuscript preparations and editing.

The results of the studies, in particular of study I, were disseminated by me to various stakeholders and in different contexts in order to make better sense of the results and set them in context, both for HIV-organizations and for researchers and healthcare providers working with people living with HIV. In addition, I presented the results from the project in international conferences and educational purposes.

5.2 DATA COLLECTION, DATA ANALYSIS AND DISSEMINATION OF RESULTS PAPER III & IV

I was hired as a research assistant at Karolinska Institutet to coordinate the project 'Health for all' in 2014–2015. Because of my early involvement in the project, I was able to contribute to all the different stages of its progress: I drafted the ethical application, developed the questionnaire in collaboration with a team of experts, was responsible for pilot-testing the questionnaire and executing the data-collection procedures. The process of developing the survey included continuous communication and various meetings and collaborations with

expert organizations, the Public Health Agency of Sweden, healthcare providers and researchers. I also bore the main responsibility for this communication.

With regard to data analyses, I performed the preliminary data analysis including data cleaning and coding. In Paper III, a statistician conducted the main analysis in close collaboration with me while I conducted all the analyses in Paper IV.

I am the corresponding first author in the publications that are derived from this project (Paper III and another published paper which is not a part of this thesis [123]), as well as the corresponding first author on the manuscript included in this thesis (Paper IV).

I also disseminated the results from the various studies included in this project at international conferences, in government agencies and in educational contexts.

6 RESULTS

6.1 QUALITY OF LIFE AMONG PEOPLE LIVING WITH HIV (PAPER I)

6.1.1 Respondents characteristics

In total, 1,086 respondent were included in the analysis. Table 6 details the descriptive data on the sociodemographic and HIV-related characteristics of the study respondents. The majority of respondents were men (70%), 29% were women and 1% reported another gender identity (and were included in the analysis, despite few observations). The age range was 18–82 with a mean age of 47.6 years and 41% were born outside Sweden. Nearly half (47%) had higher education (>12 years) while 19% had not completed secondary education and over one-half (55%) had a low monthly income. The majority worked or studied (75%), 43% were non-heterosexual and 57% had a partner. The most common mode of HIV transmission was sex between men (41%), followed by heterosexual sex (32%) and injecting drug use (11%). Nearly half (48%) had been living with HIV for >10 years, and 95% were on ART.

Table 6. Characteristics of respondents in Paper I & II (n=1096)

Variable	n (%)
Gender	
Men	762 (70)
Women	320 (29)
Other	4 (0.3)
Age	
< 30	71 (7)
31–40	226 (22)
41–50	341 (33)
51–60	238 (23)
61–70	125 (12)
> 71	25 (2)
Birth origin	
Sweden/Scandinavia	636 (59)
Outside Sweden/ Scandinavia	433 (41)
Region of birth	
Sweden/Scandinavia	641 (59)
Africa	176 (16)
Not specified	148 (14)
Asia	57 (5)
Other European countries	46 (4)
Latin America	28 (2)
City/county	
Stockholm/Malmö/Gothenburg	782 (73)
Another large city	75 (7)
Smaller city	127 (12)

Rural area	73 (7)
Do not want to answer	13 (1)
Employment	
Working/studying	724 (75)
Unemployed/long-term sick leave	246 (25)
Education	
0–9 years	206 (19)
10–12 years	361 (34)
>12 years	494 (47)
Monthly income	
Middle/high-income	451 (45)
Lower income	545 (55)
Sexual orientation	
Heterosexual	477 (44)
Non-heterosexual	468 (43)
Missing/do not want to answer	141 (13)
Relationship status	
Partner	611 (57)
No partner	462 (43)
Homeless past 6 months (Yes)	73 (7)
Time since HIV diagnosis	
0.5–5 years	47 (4)
5–10 years	500 (47)
> 10 years	513 (48)
Mode of HIV transmission	
Heterosexual sexual contact	352 (32)
Sex between men	440 (41)
Injecting drug use	115 (11)
Mother-to-child transmission	13 (1)
Blood	39 (4)
Other	70 (6)
Missing/do not want to answer	57 (5)
On ART	
Yes	1037 (96)
No	42 (4)

6.1.2 Factors associated with quality of life among people living with HIV

The majority of respondents, 66%, reported QoL scores ranging from 7 to 10 on a 0–10 scale, where 0 is the lowest possible QoL and 10 is the highest possible QoL. In the multivariate regression analysis, self-reported QoL was not associated with gender, sexual orientation or country of birth. Below, I present the results by reporting on the significant contributors ($p \leq .05$) of QoL in the multivariate regression analysis, per component of analysis.

6.1.2.1 Sociodemographic and behavioral component

Socio-behavioral variables associated with QoL among people living with HIV included recent homelessness (aOR: 0.52; CI: 0.30-0.90) and hazardous alcohol consumption (aOR: 0.71; CI: 0.53-0.97). Income, level of education, employment and relationship status were not found to be associated with QoL.

6.1.2.2 Clinical component

Having one or more diseases (comorbidities) was significantly associated with lower QoL (aOR: 0.73; CI: 0.56-0.95). Experiencing bothersome side-effects of ART and self-reported HIV-related symptoms also correlated significantly with lower QoL (aOR: 0.76; CI: 0.58-1.00 and aOR: 0.66; CI: 0.47-0.93, respectively).

6.1.2.3 Psychological component

Hopelessness was significantly associated with lower ratings of QoL among people living with HIV included in this study. Compared to respondents who reported no feelings of hopelessness, respondents who reported mild hopelessness and moderate-severe hopelessness reported significantly lower QoL (aOR: 0.53; CI: 0.39-0.72 and aOR: 0.11; CI: 0.07-0.16, respectively). Negative self-image, the internalization of stigma on oneself, was also associated with lower QoL. Compared to reporting low internalized stigma, reporting fairly high negative self-image and high negative self-image was significantly associated with lower QoL (aOR: 0.66; CI: 0.49-0.89 and aOR: 0.62; CI: 0.39-0.99, respectively). However, other stigma mechanisms assessed, including personalized and anticipated stigma (disclosure concerns and concerns with public attitudes toward people living with HIV), were not associated with QoL. Satisfaction with HIV-disclosure was not significantly associated with QoL.

6.1.2.4 Sexual life component

Experiencing negative changes in one's sex life after HIV diagnosis was significantly associated with lower ratings of QoL among study respondents (aOR: 0.65; CI: 0.45-0.95). Sexual dissatisfaction was also negatively associated with QoL (aOR: 0.47; CI: 0.35-0.62).

6.1.2.5 Personal resource and social support component

Feelings that life had become less meaningful after HIV diagnosis were significantly and negatively associated with QoL (aOR: 0.52; CI: 0.36-0.74). HIV-related support from others was not associated with QoL.

6.2 SEXUAL SATISFACTION AMONG PEOPLE LIVING WITH HIV (PAPER II)

6.2.1 Respondents characteristics

Table 6 describes the sociodemographic and HIV-related characteristics of respondents.

6.2.2 Factors associated with sexual satisfaction among people living with HIV

About one-half (51%) of respondents reported being fairly satisfied, satisfied or very satisfied with their sex life on a six-point scale ranging from very dissatisfied to very satisfied. No significant differences were observed between heterosexual and non-heterosexual men and women and sexual satisfaction.

Below, I present the results from the of path analyses of sexual satisfaction among men and women by presenting significant ($p \leq .05$) direct and indirect associations with sexual satisfaction for each component of analysis (Figure 4 and Figure 5). A path analysis is an extension of multiple regression, often used to analyse models which are more complex than multiple regression [200]. Differently from multiple regression, a path model has several dependent variables and the association between dependents variables and independent variables are assessed simultaneously [200].

6.2.2.1 Sociodemographic component

Among both women and men, not being in a relationship was associated with the experience that sex life had changed in a negative way and thus had an indirect negative effect on sexual satisfaction. Among women, there was an indirect association between country of birth other than Sweden and sexual dissatisfaction, via experiencing that HIV had changed their sexual life in a negative way (aOR: 0.30; CI: 0.14-0.65).

6.2.2.2 Clinical component

For both women and men, lower self-reported CD4 cell count was indirectly associated with sexual dissatisfaction through the variable negative HIV-related changes in their sex life (for women: aOR: 0.27; CI: 0.11-0.68; for men: aOR: 2.12; CI: 1.28-3.52). Among men, experiences of side-effects from ART were indirectly associated with sexual dissatisfaction, an association which was moderated by experiencing higher concerns about public attitudes towards people with HIV and by sexual inactivity.

6.2.2.3 *Psychological component*

HIV stigma did not play a role in sexual dissatisfaction in the female path diagram, but did so for men: high concerns about public attitudes towards people living with HIV were directly associated with sexual dissatisfaction (aOR: 0.58; CI: 0.36-0.94). Feelings of hopelessness were a significant direct contributor to less satisfying sex life among men (aOR: 0.30; CI: 0.18-0.50). Among women, hopelessness had an indirect association with sexual dissatisfaction via distress over orgasmic difficulties (aOR: 3.23; CI: 1.55-6.72).

6.2.2.4 *Sexual life component*

Women and men experiencing that their sex life had changed in a negative way after the HIV diagnosis were also sexually dissatisfied to a larger extent (among women: aOR: 0.05; CI: 0.02-0.14; among men: aOR: 0.23; CI: 0.12-0.42). Perceiving the obligation to disclose their HIV status to a sexual partner as an obstacle to finding a long-term partner was an indirect contributor to sexual dissatisfaction among women and men. For women, this obstacle was associated with sexual dissatisfaction indirectly through experiencing negative changes to sex life after HIV diagnosis (aOR: 2.31; CI: 1.16-4.62). For men, the HIV disclosure obligation was also associated with HIV stigma related to concerns about public attitudes towards people living with HIV (aOR: 2.05; CI: 1.37-3.06) and to feelings of hopelessness (aOR: 2.39; CI: 1.60-3.57).

Sexual inactivity in the last 6 months had a direct negative effect on sexual satisfaction among men and an indirect negative effect among women. No direct associations were found between orgasmic, erectile, and ejaculatory difficulties and sexual satisfaction. However, these sexual difficulties had an indirect, negative effect on sexual satisfaction via orgasmic, erectile and ejaculatory distress respectively.

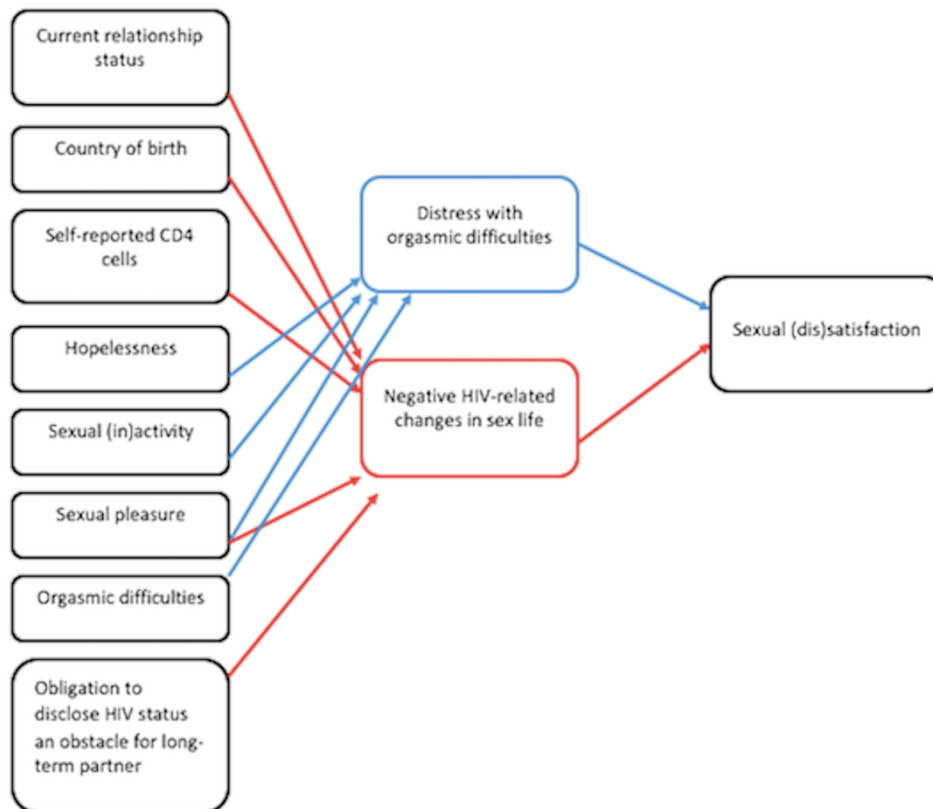


Figure 4. Path diagram, female participants (n=320)

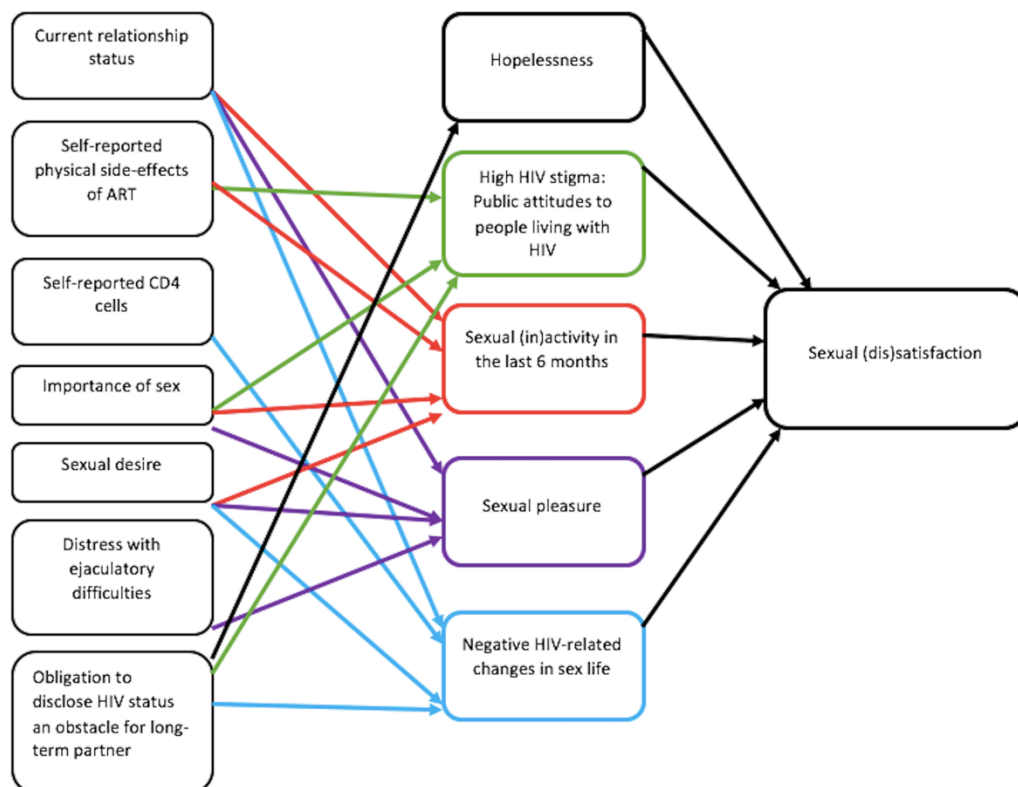


Figure 5. Path diagram, male participants (n=762)

6.3 SELF-RATED HEALTH, SELF-REPORTED DISABILITY AND QUALITY OF LIFE AMONG TRANS PEOPLE (PAPER III)

6.3.1 Respondents characteristics

Table 7 describes the sociodemographic characteristics of study participants. In short, the trans experience, i.e. self-identified gender identity and trans identity, of respondents was diverse: 19% were trans feminine, 24% trans masculine, 44% were non-binary and 14% self-identified as transvestites. The age of respondents ranged from 16 to 94 years with a mean age of 33.3 years. Respondents were represented from all 21 counties across Sweden and the vast majority of respondents were born in Sweden (92%).

Table 7. Characteristics of respondents in Paper III & IV (n=796)

Characteristic	n (%)
Trans experience	
Trans feminine	149 (19)
Trans masculine	187 (24)
Non-binary	346 (44)
Cross-dresser	112 (14)
Assigned sex at birth	
Female	388 (49)
Male	360 (45)
Age categories	
16–19	82 (10)
20–29	342 (43)
30–44	202 (25)
45–64	130 (16)
65–94	39 (5)
Country of birth	
Sweden	729 (92)
Other than Sweden	67 (8)
County	
Urban county	504 (65)
Semi-urban/rural county	269 (35)
Employment status	
Working/studying	560 (72)
Unemployed/long-term sick leave	156 (20)
Retired	34 (4)
Other	33 (4)
Education	
No high school education	150 (19)
Upper-secondary education, or some university	400 (50)
University education \geq 3 years	230 (29)
Other	16 (2)
Monthly net income (€)	
0–1416	425 (54)
1417–2125	98 (12)
2126–3238	145 (18)
>3239	80 (10)
Legal gender recognition	

No, and do not need to	157 (20)
Yes	114 (14)
No, but would like to	298 (38)
No, and cannot change legal gender because the desired gender is not available in Sweden today	207 (26)
Need for gender-affirming healthcare	
No need	129 (16)
Need unfulfilled	227 (28)
Need (partly) fulfilled	318 (40)
Do not want to answer	116 (15)

6.3.2 Factors associated with health outcomes among trans people

Trans people reported a median score of 6 on a QoL scale ranging from 0 to 10 where 0 is the lowest possible QoL and 10 is the highest possible QoL. About one-half (52%) of the respondents reported good or very good self-rated health and about one-fifth (18%) poor or very poor self-rated health. Self-reported disability, i.e. a physical or mental conditions that the respondent perceived limited their everyday life or work ability to some extent, was reported among 53% of respondents.

QoL, self-rated health and self-reported disability among trans people and their contributors are presented below by clustering the significant factors ($p \leq .05$) from multivariate regression analyses into individual levels factors (intrapersonal), community factors and structural-policy factors (socio-ecological model) [179].

6.3.2.1 Intrapersonal factors

Trans experience was significantly associated with self-rated health and self-reported disability. Specifically, identifying as gender non-binary, compared to identifying as trans feminine, was significantly associated with poor self-rated health (aOR: 2.19; CI: 1.24-3.84) and with increased odds of reporting a disability (aOR: 2.18; CI: 1.35-3.54). Age was significantly associated with overall QoL: older respondents, compared to young respondents (16–19 years), reported higher QoL significantly more often (aOR: 2.62; CI: 1.37-4.98). In addition, illicit drug use was significantly associated with poorer self-rated health (aOR: 2.29; CI: 1.33-3.95) and QoL (aOR: 0.41; CI: 0.21-0.78).

6.3.2.2 Community factors

Unemployment or being on long-term sick leave were significantly associated with poorer self-rated health (aOR: 2.59; CI: 1.70-3.97), self-reported disability (aOR: 3.51; CI: 2.05-6.00) and lower QoL (aOR: 0.39; CI: 0.24-0.63). Similarly, income was associated self-

reported disability and with poorer self-rated health; higher income was associated with less self-reported disability (aOR: 0.51; CI: 0.28-0.94) and lower income with poorer self-rated health (aOR: 1.80; CI: 1.08-2.99).

Lack of practical support from others was significantly associated with poor self-rated health (aOR: 2.57; CI: 1.47-4.48) and lower QoL (aOR: 0.21; CI: 0.11-0.42). Similarly, lack of social support was associated with poorer self-rated health (aOR: 1.64; CI: 1.11-2.42) and lower QoL (aOR: 0.49; CI: 0.31-0.77). Having a history of negative healthcare experiences was associated with poorer self-rated health (aOR: 1.92; CI: 1.26-2.91), lower QoL (aOR: 0.56; CI: 0.36-0.88) and with self-reported disability (aOR: 2.33; CI: 1.54-3.52).

6.3.2.3 Structural/public policy factors

Lack of legal gender recognition was significantly associated with poorer QoL (aOR: 0.33; CI: 0.18-0.59) and self-rated health (aOR: 2.82; CI: 1.48-5.37).

6.4 SEXUAL HEALTH AND SEXUAL SATISFACTION AMONG TRANS PEOPLE (PAPER IV)

Table 7 illustrates the characteristics of study respondents.

6.4.1 Sexual health indicators and factors associated with sexual satisfaction among trans people

Nearly one-half (46%) of respondents reported being sexually satisfied. The majority (60%) of participants had a current sexual partner: 44% had one current sexual partner and 16% had multiple current sexual partners. Nearly one-half (44%) reported not using a condom during (vaginal/anal) sexual intercourse with a current sexual partner because it was not necessary for the type of sex practiced. Never testing for HIV was reported among 40% of participants and the most common reason for not testing was being in a committed relationship with a person without HIV. However, one-third (34%) did not know of a clinic where they could get tested and get welcoming treatment. Participants reported doubt about the possibility of being able to discuss sexual matters within a healthcare context (58%). However, 17% reported wanting to discuss sexual matters with healthcare providers. A history of sex in exchange for money was reported among 12% of participants. The most common reasons for engaging in sex in exchange for money were financial. Over one third (37%) of participants reported having experienced sexual violence at some point in life.

Below, factors significantly associated ($p \leq .05$) with sexual satisfaction in the multivariate regression analysis are presented for each component of the socio-ecological model [179].

6.4.1.1 Intrapersonal factors

Many of the intrapersonal factors analyzed were not associated with sexual satisfaction, including trans experience (i.e. trans feminine, trans masculine, non-binary or cross-dresser), living according to one's gender identity, sexual orientation, hormone use and sexual violence. The only factor that remained significantly associated with lower sexual satisfaction in the multivariate analysis was experiencing negative mood symptoms (aOR: 2.03; CI: 1.00-4.12).

6.4.1.2 Interpersonal factors

Factors related to personal relationships were significantly associated with sexual satisfaction. Compared to respondents with one current sexual partner, respondents with multiple current sexual partners reported higher odds of being sexually satisfied (aOR: 0.21; CI: 0.10-0.47). Similarly, respondents who were satisfied with their intimate relationship were more often sexually satisfied (aOR: 4.24; CI: 1.91-9.40).

6.4.1.3 Community and structural factors

Experiences of sex in exchange for money was significantly associated with lower sexual satisfaction (aOR: 2.64; CI: 1.19-5.84). In addition, perceiving that it was not possible to talk about sexual health issues in a healthcare context was associated with sexual dissatisfaction among trans people in the study (aOR: 2.18; CI: 1.18-4.02). Lack of legal gender recognition was not significantly associated with sexual satisfaction.

7 DISCUSSION

This project sought to examine QoL and sexual health among trans people and people living with HIV. Below, I discuss my main findings from each paper included in the thesis.

7.1 QUALITY OF LIFE AMONG PEOPLE LIVING WITH HIV (PAPER I)

The majority of respondents reported high levels of QoL (63% reported scores ≥ 7 on a 0–10 scale), implying that many people are living positively with HIV. This corresponds with results from previous studies [40–42]. With that said, over one-third reported lower rates of QoL. Lower ratings of QoL were correlated with hopelessness, internalized stigma and negative changes to sex life after HIV diagnosis, indicating that, for many respondents, HIV is still a barrier to living a fulfilling life. Our findings strengthen previous discussions about the need for a shift in focus on health outcomes beyond viral suppression for people living with HIV [58].

7.1.1 Sociodemographic and behavioral factors

QoL was not significantly associated with gender, age, country of birth, education level, employment status and income among respondents in this study. This is in contrast to recent findings from Finland which found sociodemographic factors, including gender, financial situation, employment and relationship status, to be the main factors associated with QoL among people living with HIV included in their study [40]. Other findings suggest that ethnicity is significantly associated with QoL among people living with HIV [42,43]. In contrast, our findings suggest no differences with regard to birth origin and QoL. It is interesting and surprising that there were no differences in reported QoL between people with various sociodemographic characteristics even though we have a good representation of diverse backgrounds (41% were born outside Sweden/Europe, 29% were women, 43% non-heterosexual, 25% outside of the workforce, 19% with low education and 55% with lower income). It is possible that differences between the results in our study and the above-mentioned studies [40,42,43] are related to differences in sample size as well as the way analyzed variables were categorized. The current study includes a larger sample size and many sociodemographic (and other) variables were condensed for analyses but not dichotomized, in order to identify potential differences between various characteristics. In addition, QoL was assessed using different instruments, also contributing to potential differences in independent associations. It is nevertheless possible that the lack of associations between sociodemographic factors and QoL in the current study is related to inclusion of factors in the analysis that were not assessed in the above-mentioned studies and that could have mediated the associations between sociodemographic factors and QoL in the multivariate regression analysis. These factors include sex life factors, HIV-related stigma, alcohol consumption and homelessness.

7.1.2 Psychological factors

Hopelessness, which is a core marker of depression, was highly prevalent among study respondents and was, not surprisingly, correlated with lower QoL. High rates of anxiety and depression among people living with HIV are reported from other studies in various settings [201–204]. It is possible that hopelessness is related to HIV status and its consequences on physical, psychological, sexual and social aspects of life, such as stigma [76]. However, hopelessness can also be unrelated to HIV or perhaps related to a pre-existing condition before HIV infection. A feeling that life is less meaningful after HIV diagnosis also correlated with lower QoL.

Both feelings of hopelessness and a less meaningful life are important mental health aspects. HIV in itself might not be the ultimate reason for feelings of hopelessness, it may be related to other social, financial and health-related constraints. However, these adverse feelings are important to address, for example when healthcare providers meet people living with HIV in order to promote good and healthy lives among people living with HIV including healthy life-styles, adherence to treatment and prevention and/or management of comorbidities.

We found that negative self-image related to one's HIV, i.e. internalized stigma, was correlated with QoL. The negative association between internalized stigma and QoL has been confirmed in other settings as well [69,70]. An earlier study from Sweden attempted to find correlations between HIV-related stigma and HRQoL among 173 people living with HIV with full access to ART using a similar HIV stigma instrument as we did in the current study [71]. The findings from the above-mentioned study suggested that negative self-image was correlated with lower emotional wellbeing. Further, it was found that one aspect of anticipated stigma (concerns about public attitudes) was associated with physical functioning [71]. The same study, contrary to expectations, did not find the other examined stigma mechanisms (disclosure concerns and personalized stigma) to be associated with any dimensions of QoL [71]. The hypothesized explanation for that was that, in the current contexts of good treatment outcomes, viral suppression and good overall physical health among people living with HIV, HIV-related stigma might have a different or less of an effect on QoL [71].

Similarly, in the current study, we did not find associations between anticipated stigma (disclosure concerns and concerns about public attitudes), personalized stigma and QoL among study respondents. While the internalization of stigma and endorsement of HIV-associated negative beliefs about oneself was significantly associated with overall QoL, it is possible that anticipated and enacted stigma may have a less prominent effect in one's life when it is possible to keep HIV private and the health effects of HIV in everyday life are minimal. The conceptualization of stigma as it is used here [78,205] and in most other research is based on theory building prior to the introduction of effective treatment [77]. The

different ways that HIV-related stigma was experienced by people living with HIV who were virally suppressed was presented in a recent qualitative study from Sweden [77]. It was found that while internalized stigma was experienced in similar ways as conceptualized by Earnshaw and colleagues, enacted and anticipated stigma were more complex. The reason for that was that people did not necessarily experience individual stigmatizing encounters but rather endorsed other people's encounters with HIV-related as their own [77].

7.1.3 HIV-related support

Although HIV-related support was significantly associated with better QoL in the univariate analyses, it did not remain significant in the multivariate regression analysis, when other variables were taken into account. Social support among people living with HIV was previously found to be correlated with better QoL [42,53,206] and was identified as a buffer for depressive symptoms [206]. Studies use different instruments to assess social support, as well as take different factors into account in their analysis, which could result in over/underestimation of the significance of some variables. Few studies have included a comprehensive analysis of factors related to sociodemographic factors, sexual health, clinical factors, psychological factors and social support when assessing QoL [42]. In the current study, one-third of respondents had no one they could turn to for HIV-related support. Related to our findings about HIV-related stigma and hopelessness, it is possible that the need for HIV-related support is not perceived as important as we assumed but rather that other support needs are more prioritized. In conjunction with that, only 15% reported that they were affiliated to a HIV-support organization. Neither can it be ruled out that lack of association is related to methodological aspects, such as the categorization of the variable HIV-related support and possibly low statistical power.

7.1.4 Sex life factors

Negative changes in sex life after HIV diagnosis and sexual dissatisfaction were associated with lower QoL. Few studies assess sexual aspects of the lives of people living with HIV with regard to QoL, despite the central role that sexual life has on overall QoL and the sexual challenges people living with HIV may face [207]. Nearly two-thirds of respondents in the current study reported that their sex life had changed negatively after they were diagnosed with HIV (data not shown): 20% reported that after HIV diagnosis, their sex life changed negatively because of the difficulty in finding a steady partner and 27% that they totally avoided having sex after their diagnosis. These findings indicate that HIV constitutes a barrier for many people in forming relationships and restricts their life. These results emphasize the importance of sexual health for QoL and the need to address these issues in the care for people living with HIV.

7.1.5 Clinical factors

Clinical factors including perceived ART side-effects, HIV-related symptoms and comorbidities were correlated with lower QoL. A non-negligible proportion of respondents experienced various ART side-effects (34%) and 20% perceived HIV-related symptoms despite the majority being virally suppressed and on ART for many years. Several recent studies conducted in high-income settings where effective ART is widely available and accessible have reported both low and high burden of perceived side-effects among people living with HIV [42,208,209]. The consequences of experiences of side-effects or symptoms, beside decreasing one's QoL [42,210], may also affect adherence to treatment [209]. It is therefore important that healthcare providers discuss any perceived and experienced adverse effects of ART with their patients, and do not make assumptions or neglect this problem just because the patient is virally suppressed. It is possible that people who experience treatment side-effects take these experiences for granted, i.e. think that it is a normal reaction and thus do not communicate this with their doctors. In addition, it is possible that various adverse effects are unrelated to HIV or to ART but are perceived as being associated because it may be very difficult for an individual living with HIV to identify and differentiate between HIV or ART symptoms or other symptoms caused by, for example, age, other stressors and other medications.

Similar to other studies [55–57,59], respondents reported high rates of comorbidities such as hepatitis C, high blood pressure and psychiatric condition. Comorbidities were associated with lower QoL, as reported from other settings [40,42,43,211]. The high burden of comorbidities among people living with HIV is expected to increase as more live longer lives [212]. This increase represents an important rationale for regularly monitoring various risk factors in order to prevent and early detect different comorbidities, such as cardiovascular disease, diabetes, depression, kidney or liver dysfunctions and various forms of cancer that are more common among people living with HIV [212]. It is nevertheless important to address life-style related risk factors among people living with HIV. For instance, the percentage of current smokers among participants in this study is threefold that of the general Swedish population (28% among study participants compared to 9% in the general population [213]) and hazardous alcohol consumption, also associated with lower QoL, was reported among 18% of respondents. Various life-style related comorbidities could also be prevented by addressing poor mental health issues among people living with HIV [214].

7.2 SELF-RATED HEALTH, SELF-REPORTED DISABILITY AND QOL AMONG TRANS PEOPLE (PAPER III)

Trans people in this study reported high rates of poor self-rated health and self-reported disability compared to the general population. Lower ratings of QoL were considered as scores below the median cut-off of (6). The proportion of poor or very poor self-rated health

in the general Swedish population was 5% in the same year as our study was conducted [213], as compared to 18% of the trans people in this study. Moreover, self-reported disability, i.e. a physical or mental condition that impairs everyday life or work ability was high: 53% among trans people compared to 26% in the general population in 2015 [213]. Self-reported disability is subjective and respondents reported to what extent they felt it affected them. Not all respondents who reported a disability specified whether it was related to somatic or mental conditions. Among those who did, the main conditions which were reported were related to mental health.

Self-reported health outcomes were associated with factors such as income, employment and age, which are common health determinants for all people. However, in addition to these common health determinants, trans people included in this study faced specific distal institutional and structural challenges which were associated with their trans identity. According to the minority stress theory, minority stress is additive to general stressors that are experienced by all people, which is what makes these stressors unique [176].

Below, I discuss the results from Paper III according to the different factors included in the socio-ecological model.

7.2.1 Intrapersonal factors

For trans people included in this study, lower QoL was associated with belonging to the youngest age-group studied, 16–19 years. Young age is characterized by physical, psychological and social changes which could be extra stressful for trans people. Young age is also a more vulnerable time with regard to being more susceptible to minority stressors including victimization and limited social support [215].

Our findings indicated that respondents identifying as non-binary, i.e. people whose gender identity and/or gender expression falls outside the categories of man and woman, had increased odds of reporting a disability and poor self-rated health. Non-affirmation in gender identity by others is an element that differentiates gender minority stress from sexual minority stress [177]. For non-binary people, this non-affirmation is perhaps experienced to a larger extent compared to other trans people. This is because society might fail to address non-binary people in a gender-neutral way, because non-binary people's gender identity is not legally recognized in most countries, including Sweden, and because physical environments such as dressing rooms and public bathrooms are often gender binary. Earlier studies which report on health outcomes among non-binary people found that they report high levels of depression and anxiety [216] and that, compared with trans-binary people, non-binary people were more likely to report discrimination [217] depression, anxiety and lower self-esteem [218]. A recent Swedish report from 2017 similarly found that non-binary people experience

misgendering, i.e. the misclassification of gender identity, more often compared to other trans people [219]. Non-binary people may thus experience elevated social stress because they deviate from the strong gender norms that dominate in society.

Shortly after this study was conducted in 2015, new national guidelines were adopted with regard to the evaluation and treatment of trans people, “Good care of adults with gender dysphoria” [175]. These guidelines acknowledge the need for individualized care where different patients have different gender-affirming needs [175]. The new guidelines increase non-binary people’s access to gender-affirming care. It is thus possible that non-binary respondents reported poorer health outcomes also because of limited possibilities to access gender-affirming care, in particular when the data collection was performed.

7.2.2 Community factors

7.2.2.1 Interactions with healthcare providers

In this study, negative healthcare experiences were associated with poorer health outcomes (i.e. self-rated health, self-reported disability and QoL). Recent qualitative findings from Sweden echo our findings that many trans people experience difficulties when interacting with healthcare providers and experience lack of knowledge about trans-related issues and feeling of non-affirmation in their gender identities in encounters with healthcare professionals [220].

Inadequate access to competent healthcare services has been identified as a key health issue among trans people [125,127,128]. It is important to highlight that 69% of respondents, who were coded here as “experienced negative health care experiences”, did not necessarily experience negative treatment by health care providers per se: some experienced respectful encounters albeit characterized by a lack of knowledge about trans-related issues (Figure 6).

7.2.2.2 Social and practical support

Social support, another polar of the minority stress model in providing resources that act as stress buffers [176], was confirmed among study respondents: having social and practical support was positively associated with better QoL and better self-rated health. Social support was found to be acting as a protective factor associated with mental health among the Swedish LGB population [215]. Despite the positive effects of social support, it has been suggested that trans people may have limited social support, which is associated with poor mental health [221,222]. Limited social support could be lacking due to prejudice and rejection by family members, which in itself is attributed to poor mental health [218].

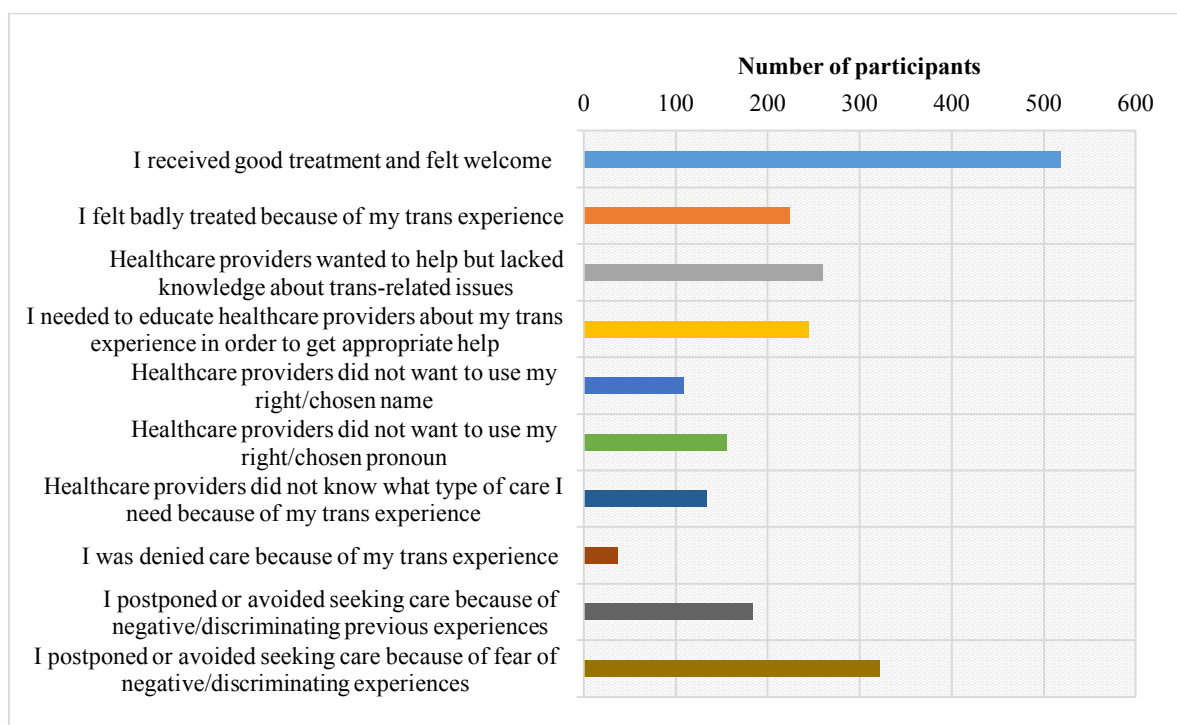


Figure 6. Experiences of respondents in encounters with healthcare providers (n=796)

7.2.3 Public policy factors

7.2.3.1 *Non-affirmation of gender identity*

A wish to change legal gender or the lack of opportunity to do so because the desired gender is not available (legal gender recognition is impossible for non-binary people), was correlated with poorer self-rated health and QoL. For many trans people, gender affirmation is a multifaceted process which includes social affirmation (e.g. name and pronoun), psychological (e.g. internal, felt-self), medical (e.g. cross hormones, surgery) and legal gender affirmation (e.g. legal gender recognition and change of name) [115]. It was previously found that social, psychological and medical affirmation among trans women were correlated with less depression and higher self-esteem [139]. Correlation between lower QoL and lack of legal gender affirmation could be explained by the daily reminders of this lack of affirmation as a result of interaction with bureaucracy and society.

7.3 SEXUAL SATISFACTION AMONG PEOPLE LIVING WITH HIV (PAPER II)

The proportion of respondents who were dissatisfied or very dissatisfied with their sexual life in this study was 33%, which is three times the proportion that was reported in the general Swedish population, using the same instrument [223]. No significant associations were observed when non-heterosexual men, heterosexual men and women were compared. Rates of sexual satisfaction (50% rather satisfied, satisfied or very satisfied) in this study were similar to rates reported in other studies [80,83,84,86,87]. We found a complex interaction between direct and indirect factors related to sexual satisfaction including sociodemographic,

clinical, psychological and sexual factors. While some factors related to sexual satisfaction were clearly HIV-related, others could not be ruled out as unrelated to HIV.

7.3.1 Sociodemographic factors

Not being in a relationship was, for both women and men, associated with HIV-related negative changes to sex life and had an indirect effect on sexual dissatisfaction. Although we cannot say for certain that not being in a relationship is related to HIV, it is possible that some participants were not in a relationship unwillingly. This assumption is strengthened by previous research which report high levels of loneliness and social isolation among people living with HIV which are largely explained by stigma [224–227].

7.3.2 Psychological factors

Anticipated HIV-related stigma was directly associated with sexual dissatisfaction, only among men, which is supported by previous studies [83]. Men who experienced high concerns about public attitudes reported higher sexual dissatisfaction. This association was combined with finding the legal obligation to disclose HIV-status an obstacle to finding long-term partner, which explains how these two concerns may fuel each other and contribute to sexual dissatisfaction among men. Interestingly, negative self-image was not associated with sexual dissatisfaction. This is in contrast to our findings with regard to overall QoL. One probable explanation is that in the sexual context, the type of stigma that dominates is related to public attitudes and fear of rejection rather than the internalization of stigma.

The importance of the mental health state of people living with HIV with relation to various aspects of life is further confirmed by our finding that hopelessness was directly associated with sexual dissatisfaction among men and indirectly among women, via distress over orgasmic difficulties. Mental health is also closely related with various aspects of sexual health including sexual function [228,229] and satisfaction [95] but too often neglected in the clinical HIV care/infectious disease setting.

7.3.3 Sex life factors

Similarly to previous studies among people living with HIV, we found an association between sexual inactivity and sexual dissatisfaction [83,84]. Previous studies suggest that both intentionally and unintentionally abstinence among people living with HIV is common and is a coping strategy to avoid rejection and fear of disclosure [80,230]. In addition, 27% of study respondents reported that they stopped having sex after their HIV diagnosis, which leads us to believe that sexual inactivity could, at least to some extent, be associated with HIV.

HIV-related negative changes to sex life were, not surprisingly, significantly associated with sexual dissatisfaction among both women and men. After an HIV diagnosis, the individual's sex life becomes fraught with restrictions. This finding is also identified in Paper I with regard to QoL. Negative changes to sex life after HIV was related to experiencing the legal obligation to disclose HIV status as an obstacle to long-term relationships. The application of this legal obligation has been modified since 2013 and today treating physicians can exempt their patients from this obligation under the condition that patients are durably virally suppressed and condoms are always used during sexual intercourse. However, despite these exemptions, people still face dilemmas regarding how and when to disclose their HIV status to sexual partners and need to weigh the possibilities that casual sexual relationships might develop to long-term ones. Further, recent evidence suggests that not all people living with HIV who are eligible for these legal exemptions are informed about this right [98]. Our findings, in combination with this recent evidence, suggest that this legal obligation still has a significant impact on people's lives, in particular their sexual life – thus, much more information is needed, to health providers and people living with HIV about the new interpretation of the law since 2013, and, to the public about treatment as prevention (TasP) and the strong evidence of minimal transmission when on ART.

7.4 SEXUAL HEALTH OUTCOMES AND SEXUAL SATISFACTION AMONG TRANS PEOPLE (PAPER IV)

The proportion of respondents who reported being dissatisfied or very dissatisfied with their sex life (34%) was three times that of the general Swedish population [223]. Factors associated with sexual satisfaction among trans people in this study included expected factors which were previously found to be associated with sexual satisfaction among various populations including relationship satisfaction and absent of negative mood symptoms [7]. However, our findings also revealed associations between sexual satisfaction and multiple sexual relationships and possibilities to discuss sexual matters within the healthcare context, which were not previously reported. In addition, our findings also shed light on different aspects of sexual health including condom use, HIV testing and access to sexual health services among study respondents which have not been presented before in a Swedish context. Our findings also revealed an unmet sexual healthcare need as well as a need to contextualize sexual risk.

By examining both distal and proximal variables, we attempted to find out whether, in addition to individual and relational factors, other institutional and structural factors were significant contributors to trans people's sexual satisfaction, in accordance with the concepts of the socio-ecological model [12].

7.4.1 Intrapersonal factors

At the intrapersonal level, the only variable that was significantly associated with sexual dissatisfaction was experiences of negative mood symptoms. Previous studies found a correlation between depressive symptoms and sexual dissatisfaction among cis-and-trans people [12,160,231].

In contrast to expected and to previous research [160], we did not find an association between sexual satisfaction and being able to live according to gender identity and met or unmet needs for gender-affirming intervention. It has previously been demonstrated that Dutch trans people with unmet gender-affirming healthcare needs were significantly more likely to experience body dissatisfaction, which was associated with sexual dissatisfaction [160]. We did not assess body satisfaction in this study, which is perhaps a better indicator than gender-affirming healthcare needs, with regard to sexual satisfaction. Another possible explanation for the lack of association could be that people cope with different conditions and circumstances and that despite gender dysphoria, trans people may find a way to enjoy their sexuality [133]. It is also possible that the indicators that we used to assess gender-affirming healthcare needs were not sufficient in capturing the situation among study respondents. We used a proxy for gender-affirming healthcare needs by analyzing whether a person has the desire to and has started the bureaucratic procedure of seeking gender-affirming healthcare. However, we did not ask which procedures a person wished to perform nor whether or not these wishes were fulfilled.

Hormone use was also not found to be associated with sexual satisfaction in the multivariate analysis, which contradicts previous findings [170]. It is possible that while hormone use might affect sexual desire, it does not necessarily mean it also affects satisfaction. The effects of hormonal therapy is not only determined by biological factors but also by psychosocial factors which are important predictors of sexual satisfaction [133].

7.4.2 Interpersonal factors

At the interpersonal level, we found that, in comparison to having one current sexual partner, having multiple sexual partners was correlated with higher sexual satisfaction. Multiple sexual partners is often seen in a context of risk behavior and is rarely presented in other contexts [232]. Nearly every fourth (16%) respondent reported currently having more than one sexual partner. A similar proportion was found among a Canadian cohort of trans people [233], emphasizing the need to step out of the normative perspective of monogamous relationships when assessing relationship types in research.

Another relational variable that was significantly associated with sexual satisfaction was relationship satisfaction, which is in line with previous research on sexual satisfaction in cisgender populations [12,234]. It is not surprising that sexual satisfaction is higher in a relationship that thrives and when one is satisfied with one's relationship. Qualitative findings among trans people describe the importance of respectful and loving intimate relationship for overall sexual health [163].

7.4.3 Institutional factors

With regard to institutional factors, we found that experiencing a lack of opportunity to discuss sexual matters in a healthcare context was associated with lower sexual satisfaction. Feeling that it is hard to discuss sexual matters with healthcare providers is perhaps not unique to trans people. It was previously found that both healthcare providers and (cisgender) clients may find it difficult [235]. However, for trans people, it might be particularly challenging because of previous negative encounters with healthcare providers or expectations of incompetence with regard to trans-related issues [236,237].

Experiences of sex in exchange for money were associated with lower sexual satisfaction. Transactional sex among trans women in particular has been identified as a symptom of societal and economical marginalization [238] and is associated with increased risk of HIV [158]. In this cohort, 12% have reported experiences of sex in exchange for money. A Canadian study found similar numbers [239]. In this context, it is important to keep in mind that Sweden is a country with different social, medical and legal conditions compared to many other countries: gender-affirming healthcare is included in the national healthcare insurance and discrimination against trans people in employment, healthcare provision, housing and other sectors is prohibited by law [172]. Yet, marginalization of trans people still exists and limits the inclusion of trans people in society's different arenas.

7.4.4 Public policy factors

Surprisingly, legal gender recognition, which is a structural public policy factor, was not associated with sexual satisfaction. We assumed that legal affirmation of gender identity was a proxy to other types of gender affirmations (social, psychological or/and medical) and would thus be positively associated with sexual satisfaction. Previous findings indicate that, while gender affirmation is important for sexual satisfaction among trans people, body satisfaction is an even more important predictor of sexual satisfaction [160]. We did not assess body satisfaction in this study, but it is likely an important aspect for respondents in this study as well.

7.4.5 Other sexual health indicators

Some variables have only been analyzed descriptively because we wanted to fill the knowledge gap about these sexual health indicators in the Swedish context. Yet, we did not consider these variables as predictors of sexual satisfaction. These sexual health indicators represent important findings about unmet needs among trans people. For example, 40% of respondents have never been tested for HIV. Similar numbers were found in a Canadian study [239]. This proportion seems high. However, it was estimated in 2012 that only 11% of the general Swedish population had been tested for HIV over the past twelve months [240] compared to 24% who had been tested for HIV in the past year among respondents in this study. The proportion of testing for HIV needs to be understood in a context of risk. When respondents were asked whether they used condoms if having receptive/penetrative vaginal/anal sex (an indicator of high-risk sex), the majority replied that they did not practice this type of sex and therefore did not need to use a condom. Similarly, Bauer et al. found that a relatively small proportion of participants in their study reported having receptive/penetrative genital sex with flesh contact and fluid exposure [239].

Even though many participants did not consider that they needed to get tested for HIV, nearly 20% responded that they did not know where to get tested or that the reason they had not been tested was their worry about healthcare providers' attitudes towards trans people. Similarly, one-third of participants did not know of a sexual health clinic where they could feel welcome. These numbers are worrying and prevent us from estimating the needs and the magnitude of risk in terms of self-reported sexual health outcomes.

With regard to perceived knowledge on how to protect oneself from HIV and other STIs, 22% participants reported not having sufficient knowledge about how to protect themselves from other STIs and 14% from HIV. Summarizing these descriptive findings, it is important to keep in mind that trans people represent a heterogeneous group with regard to relationship types and sexual practices, which is important in contextualizing and estimating risk and needs [239]. In the words of Bauer et al. [239]: "Trans sexuality is not easily captured in conventional ways of thinking about HIV-related risk, and our results caution against making any assumptions about the types of sex trans people have, the body parts they use, or who their sex partners are. This has implications for design of prevention and education programs."

7.5 METHODOLOGICAL CONSIDERATIONS

7.5.1 Selection bias and representativeness

7.5.1.1 Respondents in the study *Living with HIV*

One strength in this project is related to the large size of cohort in the study *Living with HIV* (Paper I & II), which is by far the most extensive self-reported data among people living with HIV in Sweden. With that said, we have limited knowledge about the characteristics of non-respondents in the study. Although we attempted to conduct non-response analysis, we did not manage to keep a systematic record of non-responders at all 17 different collaborative sites, mainly due to confidentiality issues. This prohibited us from listing information on the sociodemographic characteristics of those who declined participation in the study. It is possible that non-responders share certain characteristics that would have been meaningful for this study, such as poorer overall health and higher stigma. With regard to the sociodemographic characteristics of non-responders, we can make some assumptions thanks to the national quality registry InfCare HIV [15], which provides us with such data. We could see that in our cohort certain groups were slightly under-represented including people who were born outside Sweden (56% according to InfCare HIV data 2014 and 44% in this cohort) and people who said they had been infected with HIV via heterosexual sex (47% according to InfCare HIV data in 2014 and 32% in this cohort), which is the largest HIV transmission route among migrants. With regard to other characteristics such as sex, HIV transmission routes (besides heterosexual sex), county of residence and age, we judge this study cohort as representative of the larger population of people living with HIV in Sweden. In addition, we made considerable efforts to recruit previously underrepresented groups such as women, migrants and people who inject drugs – which we are satisfied with. The questionnaire was available in 10 different languages and the help of a translator was available for those who needed it. In addition, two needle-exchange centers distributed the questionnaire which increased the representation of people who inject drugs.

7.5.1.2 Generalizability of the findings from *Living with HIV*

Because of the large sample size and due to the extent to which it represents the population of people living with HIV in Sweden, we believe that our results are generalizable. Yet, correlations, and lack of correlations that were found in Paper I and II should be interpreted with caution. In study II for instance, the findings suggest a more complicated model of factors related to sexual satisfaction among men compared to the model for women. This could be partly explained by the fact that the group of women was significantly smaller in size compared to the group of men, which might have implications for lower statistical power, possibly underestimating significant associations, which is also relevant for the lack of association between gender and QoL in Paper I.

7.5.1.3 *Recruitment of participants in the study Health for all*

Another limitation in respect to selection bias is the convenient sampling method that was used in the cohort of trans people (Paper III & IV). Study participants were self-selected via web-based recruitments in HBTQ-related arenas and by personalized invitations made by the research groups' collaborators. The study population, which resulted from this type of recruitment, may not be representative of the entire population of trans people in Sweden. Because trans people are a population of unknown size, randomized sampling from the population would not be a possible or even appropriate recruitment method and web-based surveys become a practical tool to reach a large volume of people.

We cannot make any assumptions about the generalizability of the group included in this study and the larger population of trans people due to the convenient sampling that was employed for recruitment. With that said, this is the largest volume of self-reported data collected in Sweden among trans people and this cohort represents a heterogeneous group of people self-identifying as trans, with various gender-affirming healthcare needs. This heterogeneity has not been seen in Swedish research on trans people, which is a strength in this project.

7.5.2 **Instruments and scales**

The main outcomes in this project, namely QoL and sexual satisfaction, were each assessed using a single question. This may have an effect on the reliability of these instruments. Our aim was to assess overall QoL by exploring different psychosocial, clinical and sexual factors, and not HRQoL per se. It was previously shown that a single-item VAS scale assessing global QoL is an instrument with as good validity and reliability as multi-item questionnaires [241]. In addition, many of our results were confirmed in other studies' findings, also supporting our instruments' reliability. Another aspect of this use of instrument is that it had not been used on previous Swedish data which compromises comparisons with regard to level of QoL. Similarly, sexual satisfaction was assessed using a single question, which may not represent the multidimensionality of this construct in the same way as a multi-item instruments might. The instrument that we used has been previously validated in Sweden which also provides us with good scope for comparison [223]. It should, however, be noted that the Swedish norm data that we compare our results with originates from a study conducted in 1998 [242], which may undermine the relevance of these findings. With that said, most of our findings with regard to sexual satisfaction were confirmed in findings from other settings and which used other instruments.

Both studies were set up to map out the health and social situation among these populations in a broad sense, and as such included many different sections and questions. Retrospectively,

it seems like some aspects would have benefitted from receiving more detailed attention. For example, the questions regarding sexual health among trans people were more focused on risk behavior rather than on positive aspects of sexuality which might have provided us with a more holistic picture of sexual satisfaction in this population. Other important factors in relation to sexuality, including importance of sex, challenges in forming intimate relationships and body satisfaction, would all be highly relevant to assess in relation to sexual satisfaction.

7.5.3 Trade-off between different analytical approaches and losing valuable information

The questionnaires that formed the basis of this work included many items that did not have mutually exclusive alternatives and could not easily be dichotomized. Many statistical approaches within epidemiology are designed for continuous or dichotomized data. However, the nature of the data collected here often included variables with multiple categories which were hard to dichotomize without losing valuable information. This type of data was particularly challenging when I tried to explore other analytical approaches such as structural equation modelling (SEM) for paper IV. Not all variables that I was interested in could be dichotomized and with the lack of previous studies among trans people, I had no clear theoretical model to follow. It is possible that our results could have been more complex and detect underlying factors had we been able to use other, more complex models.

7.5.4 Imputation of missing data

Questionnaires that are lengthy and that contain sensitive issues are bound to suffer from missing information. When applying various multivariate regression analyses, each missing data point is treated as missing on all other items as well. To decrease the missing data in our data, we applied multiple imputation in Papers I and II. Multiple imputation has its limitations and may give biased results. In Paper I, even though we performed multiple imputation, we coded some variables with missing observations as “do not want to answer”. This was done because we believed that missing answers could be significantly associated with the outcome.

7.5.5 Study design

This project is purely quantitative. However, some hypothesized associations that we could not confirm in this project, for example the lack of association between social support and QoL among people living with HIV, among others, would be interesting to explore more qualitatively. The use of only quantitative design is thus limited in explaining all aspects related to QoL and sexual satisfaction.

7.5.6 Possible exclusion of trans respondents in Paper II

Because sexual satisfaction is gender-dependent, we assessed sexual satisfaction among people living with HIV (Paper II) separately for women and men. This division made us exclude participants who reported “other” as their gender identity because these respondents were too few to include in a model. Consequently, four respondents were excluded that were probably non-binary trans people. In Paper I, however, we included these respondents, despite this group’s small size.

8 CONCLUSIONS

- A majority of people living with HIV included in the study reported good overall quality of life
- Our findings supported by previous studies emphasize the importance of mental health and wellbeing for both QoL and sexual health outcomes among people living with HIV in the era of good treatment outcomes and viral suppression
- For many, QoL is still compromised by HIV infection and associated with internalized stigma, negative sexual changes and comorbidities
- Despite very good treatment outcomes, viral suppression and nearly non-existing risk of secondary transmission, people living with HIV included in the study experienced that the HIV diagnosis had changed their sex life in a negative way, which was associated with sexual dissatisfaction
- Trans people, and particularly non-binary people included in the study, reported high rates of poor health, perceived disability and relatively low QoL
- Factors related to trans people's health and QoL are similar to those of the general population in addition to trans-related distal factors, such as legal gender recognition and experiences of healthcare incompetence in trans-related issues
- Trans-friendly sexual health services including testing and counselling were needed among study respondents
- There is a need to shift from normative assumptions about sexual relationships, practice and sexual risk in order to understand sexual health issues among trans people

9 RECOMMENDATIONS FOR HEALTHCARE AND POLICY

Our findings regarding quality of life and sexual health among **people living with HIV** imply that:

- There is an increasing need to adopt an integrated care approach for people living with HIV that is more patient-centered and personalized. The provision of integrated care and counselling targeting psychological, sexual and reproductive health issues as well as prevention, treatment and management of both physical or psychiatric comorbidities is essential.
- Our results demonstrate and strengthen previous findings about the importance of mental health for both overall QoL and sexual satisfaction and underscore the importance of incorporating periodic screening and monitoring of symptoms of poor mental health within the HIV care.
- The legal obligation to disclose one's HIV status to sexual partners has been a major obstacle for many people living with HIV to forming intimate relationships and having a satisfying sex life. The robust evidence of undetectable = untransmittable, which has also led to legal changes in disclosure obligations, needs to be communicated much more effectively to the general public, to people living with HIV as well as to healthcare personnel.
- The negative effects of HIV-related stigma are evident in both self-rated QoL and sexual satisfaction. Stigma elimination efforts should be intensified and focus on contemporary knowledge about HIV, directed towards both the general public and healthcare providers. Since it is not possible to eradicate the social stressors associated with stigma, it is important for people living with HIV to have access to both psychosocial support and tools to build resilience, self-esteem and self-confidence.
- Robust tools for regular monitoring and follow-up of the QoL of people living with HIV should be scaled up and used in clinical practice and management of HIV.

Our findings from the health, quality of life and sexual health among **trans people** imply that:

- The healthcare system needs to be more trans-inclusive, for example, by including questions of preferred name and pronoun in encounters with people seeking care. Knowledge about trans people and trans-specific healthcare should be included in the

objectives in the educational programs for all healthcare personal and be a part of further training programs.

- Legal gender recognition should be made simpler and not related to medical procedures in order to increase the access of trans people to get their gender identity recognized. The inclusion of a third legal gender, that can suit non-binary people should be seriously considered in Sweden.
- Increased knowledge and visibility of trans people is needed in order to deliver welcoming and adequate needed mental health services.
- Educators, counselors and healthcare providers should strive for not having assumptive attitudes about trans people's sexual practices, preferences and orientations, thus increasing access to sexual healthcare services for this group.

9.1 COMMON RECOMMENDATIONS FOR RESEARCH AND MEDICAL PRACTICE:

- Include the target group concerned in the different phases of research, from the early stages of designing the study to translation of findings and the actual finalized product in the form of information dissemination and/or interventions.
- Sexual history taking could be an effective way to explore the different challenges patients face with regard to their sexual life and should therefore be used in specialized care catering for people living with HIV and within gender-affirming care.

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12 APPENDICIES

12.1 APPENDIX 1: LIST OF DATA COLLECTION SITES (PAPER I & II)

Clinic/site

1. Karolinska University Hospital, Stockholm
2. Venhälsan, Stockholm South General Hospital (SöS), Stockholm
3. Sahlgrenska University Hospital, Göteborg
4. Skåne University Hospital, Malmö
5. Gävle Hospital, Gävle
6. University Hospital of Umeå, Umeå
7. Örebro University Hospital, Örebro
8. Helsingborg Hospital, Helsingborg
9. Sunderby Hospital, Luleå
10. Falu Hospital, Falun
11. Needle exchange programme at S:t Görans Hospital, Stockholm and Karolinska University Hospital, Stockholm
12. Kalmar Hospital, Kalmar
13. Skaraborg Hospital, Skövde
14. Stockholm's Drug Users Union, Needle exchange programme by Gullmarsplan, Stockholm
15. Blekinge Hospital, Karlskrona
16. Astrid Lindgren Children's hospital, Stockholm
17. Visby Hospital, Visby

12.2 APPENDIX 2: STUDY INFORMATION (PAPER I & II)

LIVING WITH HIV IN SWEDEN

Over a period of four months, more than 1,000 HIV-positive Swedes throughout the country will be asked about participating in a study that looks at what it is like to live with the condition these days. Up-to-date information about the circumstances and quality of life among various population groups is required in order to improve healthcare and other social institutions as needed. In other words, your participation will be highly valuable.

How does it work?

During your appointment at the infection clinic, you will fill out a questionnaire about how you are doing and the things that may or may not be difficult for you to deal with at work, when travelling, when communicating with the healthcare system or in your personal relationships. The questionnaire takes 20-40 minutes to complete.

The questions were put together in collaboration with a number of organisations (including HIV Sweden, Noah's Ark and the Swedish Drug Users Union in Stockholm) that support HIV-positive people. You might feel that some of the questions are repetitive or invasive, but they are important so that we can compare the responses to those of people in other countries. The results of the study will be compiled and made available for anybody who is interested in late spring 2014.

The questionnaire is completely anonymous and voluntary. Nobody will be able to make any connection between you and your responses. None of your caregivers will have access to your responses.

You can drop out of the study at any time. The health care you receive will not be affected if you decide not to participate in the study.

Who is in charge of the study?

The study is a collaborative project of the Swedish Institute for Communicable Disease Control, Karolinska Institutet, Karolinska University Hospital, Venhälsan and Astrid Lindgren Children's Hospital in Stockholm, as well as infection clinics in Helsingborg, Malmö, Karlskrona, Kalmar, Visby, Skövde, Gothenburg, Örebro, Falun, Gävle, Umeå and Luleå. Anna Mia Ekström, a professor at Karolinska Institutet and a specialist in infectious conditions, is in charge of the study. The Regional Ethical Review Board in Stockholm has approved both the study and the questionnaire.

Is there anything you are wondering about?

If there is anything you would like to ask about the questionnaire, feel free to talk to the person who contacted you about participating in the study.

If there is anything you would like to ask about the study, feel free to call the research coordinators at 0735 - 605 942, , or write to Dr Ekström at Automatic citation updates are disabled. To see the bibliography, click Refresh in the Zotero tab.

If there is anything you want to ask about HIV in general, or if you are looking for advice from somebody who knows what it is like to live with the condition, contact:

- Swedish Association for HIV-Positive People at 08-714 54 10 or www.hiv-sverige.se
- Posithiva Gruppen at 0736-24 24 22 or **Error! Hyperlink reference not valid.**
- National Federation of Noah's Ark Associations at www.noaksark.org or your local association at 020-78 44 40
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Consent to participate in the study "Living with HIV in Sweden"

Responding to the questions indicates that you have consented to participate in the study and that you realise that your participation is voluntary and that your responses are completely anonymous

12.3 APPENDIX 3: STUDY INFORMATION (PAPER III & IV)

HÄLSA FÖR ALLA En studie för personer med transexfarenhet

Hej!

Välkommen till vår enkät som handlar om hälsa och livsvillkor för transpersoner!

Vad?

Under 2 månader kommer länkar till en online-enkät att cirkulera på olika hbtq-hemsidor, forum, Facebook samt via e-post. Vi önskar sprida enkäten så mycket som möjligt för att alla som vill ska få en chans att delta en gång.

Varför?

Aktuell kunskap om hälsa och livsvillkor för transpersoner, som vi hoppas få genom den här enkäten, kan hjälpa till att förändra till det bättre. Vi hoppas genom enkäten att kunna identifiera de delar av hälsa och livsvillkor i samhället som fungerar bra och de som fungerar mindre bra, och den informationen kan sedan ligga till grund för beslutsfattare om åtgärder och satsningar som förbättrar. Din medverkan är därför mycket värdefull!

Hur?

Genom att godkänna ditt medverkande längst ner på den här sidan, hänvisas du till en elektronisk enkät.

Enkäten riktar sig till dig som är transperson eller har transexfarenhet samt har fyllt 15 år.

Enkäten innehåller frågor om hur du mår och hur du upplever att du blir bemött i samhället.

Enkäten tar cirka 15-30 minuter att fylla i.

Frågorna har bearbetats i samarbete med RFSL, RFSL Ungdom och forskare på Karolinska Institutet för att vara så aktuella och relevanta som möjligt. Enkätens svar kommer senare i höst att sammanställas och nästa år publiceras som en rapport som kommer att vara tillgänglig på Folkhälsomyndighetens hemsida.

Säkerhet och anonymitet

Enkäten är helt anonym och deltagande är helt frivilligt. Det finns inga som helst möjligheter att dina svar kan kopplas till dig som individ och inga uppgifter som kan identifiera dig sparas. Du kan när som helst avbryta ditt deltagande. Informationen som samlas in via enkäterna sparas på en skyddad server och resultaten kommer enbart att presenteras på så kallad grupp nivå. Det betyder att man slår ihop alla svar på samma fråga och presenterar ett gruppresultat, istället för en enskild individs svar.

Vem är ansvarig?

Karolinska Institutet genomför studien på uppdrag av Folkhälsomyndigheten. Studien är ett samarbete mellan Karolinska Institutet, Folkhälsomyndigheten, RFSL och RFSL Ungdom. Forskningsansvarig för enkäten är professor Anna Ekéus Thorson.

Om du har frågor om enkäten och/eller om studien, vänd dig till forskningsassistent Galit Zeluf på telefon 0735-208821 eller mejla till galit.zeluf.1@ki.se

Samtycke till deltagande i studien

Jag har härmed fått skriftlig information om studien "Hälsa och livssituation hos transpersoner i Sverige" och samtycker att delta i studien. Jag vet att min medverkan är frivillig och att mina svar är helt anonyma. Jag är 15 år eller äldre

☐ Ja

☐ Nej